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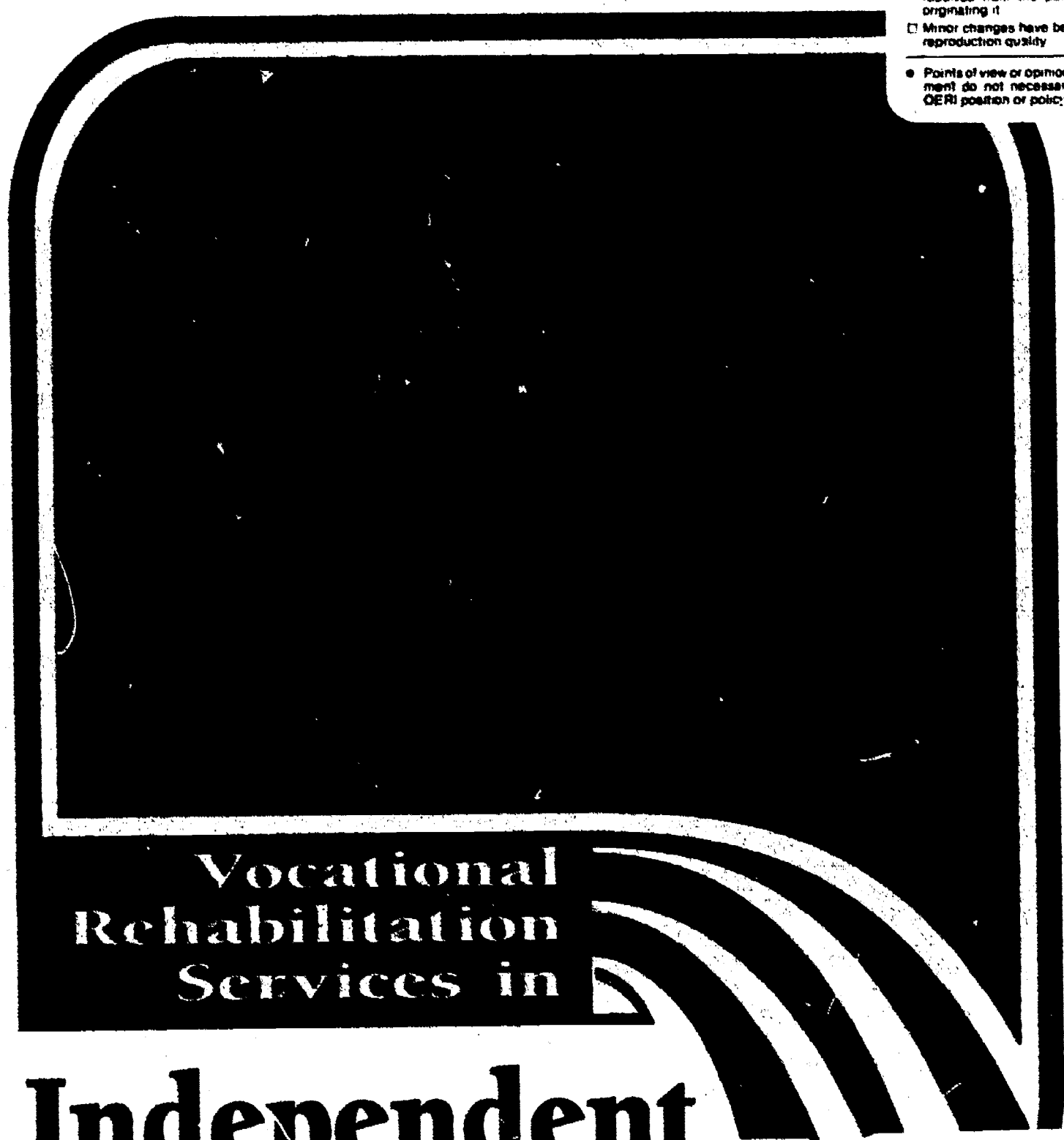
ABSTRACT

This report explores ramifications of vocational rehabilitation services being provided in independent living programs through tracing the development of disability rights and independent living movements from their inception to the present. Comparisons are drawn between the programmatic approaches of state rehabilitation agencies and independent living programs. A national study of the prevalence of vocational services in independent living programs was conducted. Model programs representing a variety of approaches are described. Specific chapters address the following topics: definitions; historical and legislative perspectives of the disability rights movement; implications of vocational rehabilitation for independent living; implications of independent living for vocational rehabilitation; current employment practices in independent living centers and independent living programs; model employment programs in independent living centers; and future directions and recommendations. Appendices include membership of the study group, the highlights of a report on Centers for Independent Living Programs, the Disabled People's Bill of Rights and Declaration of Independence, a list of interview participants, and the survey instrument used. (DB)



Independent Living Centers

Seventeenth Institute on Rehabilitation Issues
Report from the Study Group

Arkansas Research & Training Center in Vocational Rehabilitation
University of Arkansas at Fayetteville
Arkansas Rehabilitation Services

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Report from the Study Group
Seventeenth Annual Institute on Rehabilitation Issues

Vocational Rehabilitation Services in Independent Living Centers

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CHAIRPERSON'S COMMENTS

As the disability rights and independent living movements have evolved into a network of independent living centers and programs throughout the country, they have become significant contributors to the advocacy and service delivery systems for people with disabilities. While virtually all such programs focus upon basic independent living services such as advocacy, independent living skills training, peer counseling, and information and referral, many such programs have also begun to provide vocational services to assist persons with disabilities whose goals involve employment. As this trend has evolved, questions have been raised regarding such issues as duplication of effort with state rehabilitation agencies, the relative roles of rehabilitation agencies and independent living programs, and advantages and disadvantages of coordinated efforts between the two entities. Consequently, it is the purpose of this study to explore the various ramifications of vocational rehabilitation services being provided in independent living programs.

In examining this topic, the Prime Study Group traced the development of the disability rights and independent living movements from their inception through current program activities. Comparisons and contrasts were noted between the programmatic approaches of state rehabilitation agencies and independent living programs. Moreover, the implications of each of these systems were explored as they relate to each other. The document includes a national study of the prevalence of vocational services in independent living programs, and model programs representing a variety of approaches are included. Finally, the document includes visions and recommendations from leaders in the rehabilitation and independent living movements and a new paradigm for service delivery is proposed.

The Prime Study Group charged with the responsibility of exploring this topic consisted of Douglas Rice of the Arkansas Research and Training Center in Vocational Rehabilitation (university sponsor), John Chappell of the Massachusetts Rehabilitation Commission, Ted Haworth of Michigan Rehabilitation Services, Vicki Bond of the Addie McBryde Center For the Blind in Mississippi, Laura Williams of the Independent Living Research Utilization Project in Houston, and Bob Means of the Arkansas Research and Training Center in Vocational Rehabilitation and the Hot Springs Rehabilitation Center. These individuals brought expertise, creativeness, and a spirit of teamwork to the task. Their goal-setting abilities and hard work helped us accomplish our mission on schedule and their collective sense of humor and good nature made it a most enjoyable endeavor. For these efforts and attributes, I am sincerely appreciative.

It is my hope that this document will serve as a resource for planners, practitioners, and trainers in the rehabilitation and independent living fields and also as the impetus for further discussion and exploration as the service delivery system for persons with disabilities continues to evolve.

Ted M. Thayer,
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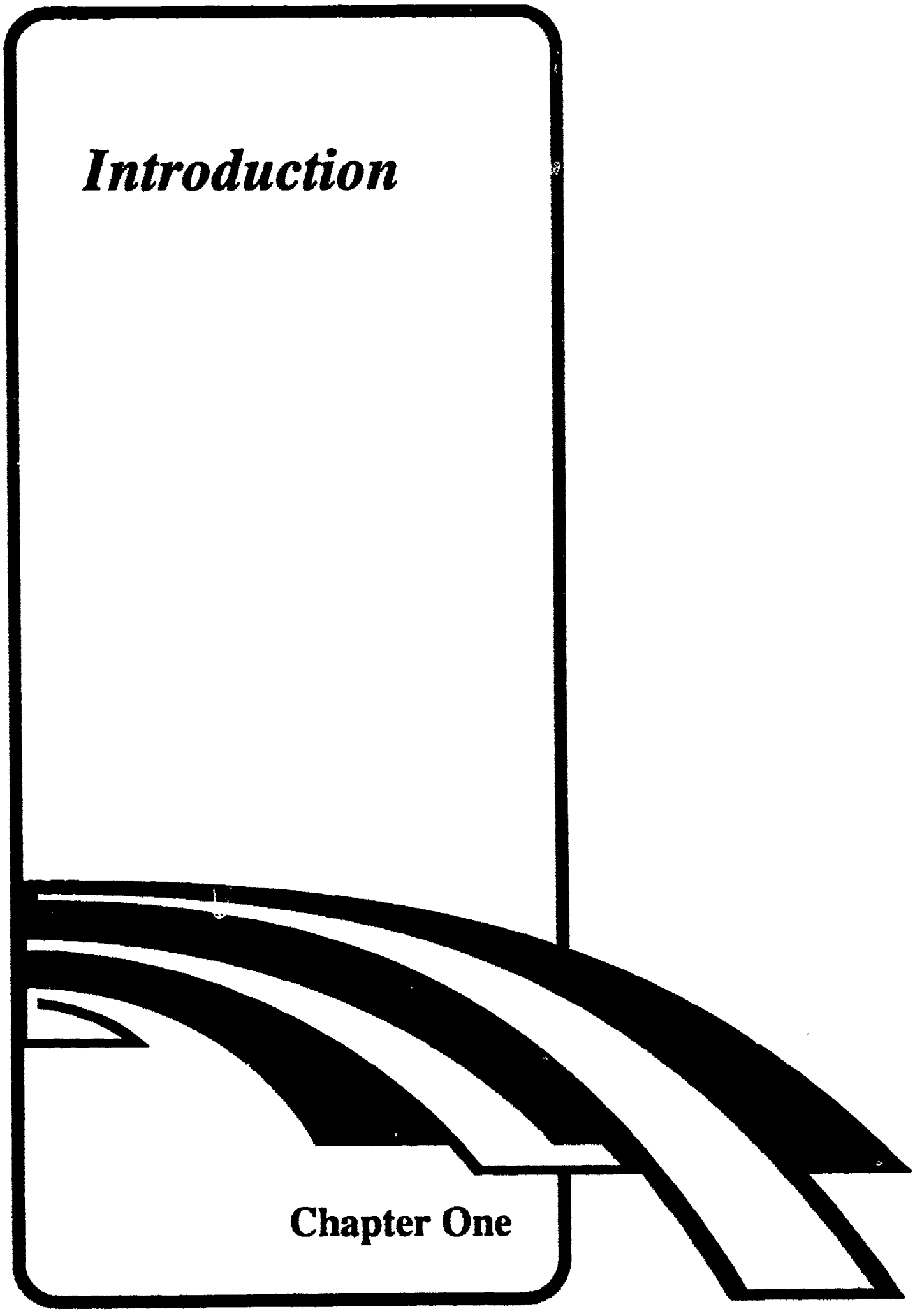
Introduction



Chapter One

INTRODUCTION

Independent living (IL) for individuals with disabilities has always been a major objective of the state/federal vocational rehabilitation (VR) program. Throughout the history of VR, professionals in the field have promoted the provision of IL services to expedite the entry or reentry of persons with disabilities into employment. Despite the philosophy and objectives of the VR program many persons with disabilities, even those who were considered to have vocational potential, failed to have their IL needs met. Often this deficit in services was the major barrier to successful transition into employment.

The IL movement of the late 1960's and early 1970's received its impetus from people who themselves were severely disabled, and resulted in an increased awareness of the value of IL services to consumers, advocates, and providers. Pioneers in several states (e.g., California, Massachusetts, among others) influenced Congress to enact the 1978 Amendments (P.L. 95-602), which added Title VII to the Rehabilitation Act of 1973 (P.L. 93-112). These amendments provided for comprehensive services in the area of IL.

The relationship between VR and IL services is clearly referenced in Title VII, Part A, Section 702 of this legislation:

> Services may be provided under this title to any individual whose ability to engage or continue in employment or whose ability to function independently in the family or community, is so limited by the severity of the disability that vocational or comprehensive rehabilitation services appreciably more costly and of appreciably greater duration than those vocational or comprehensive rehabilitation services required for the rehabilitation of an individual with handicaps are required to improve significantly either the ability to engage in employment or to function independently in the family or community.

This section further elaborates upon the relationship as follows:

> ...the term "comprehensive services for independent living" means any appropriate vocational rehabilitation service (as defined under Title I of this Act) and other service that will enhance the ability of an individual with handicaps to live independently and function within the family and community and, if appropriate, secure and maintain appropriate employment...Such services may include...appropriate job placement services...

Similarly, Title VII, Part B, Section 711 authorizes the establishment of independent living centers (ILCs) and also alludes to the provision of VR services. Training in job-seeking skills is included as an authorized service.

Selection of "Vocational Rehabilitation Services in Independent Living Programs" as an Institute on Rehabilitation Issues Topic

It is evident that IL services have undergone significant changes since 1978. Although the Institute on Rehabilitation Issues (IRI) addressed IL in its fifth study, The Role of Vocational Rehabilitation in Independent Living (Rice, 1978), and in its seventh study, Implementation of Independent Living Programs in Rehabilitation (Rice, 1980), the many changes caused the Council of State Administrators for Vocational Rehabilitation, the Rehabilitation Services Administration, and the National Institute on Disability and Rehabilitation Research to suggest that IL be examined as it relates to the provision of VR services by independent living programs and centers (ILPs/ILCs). Although there are diverse opinions as to roles that VR and ILPs/ILCs should play, especially in the area of employability, a number of ILPs/ILCs have implemented employment related services. Others also seem to be moving in this direction; still others are adhering to the view that their services are for persons who are too severely disabled for employment or that VR services should be provided elsewhere. Regardless, it is evident that ILPs/ILCs as a group are taking a more comprehensive approach to services, including VR services, and a need for coordination and interaction with the state rehabilitation services program is obvious.

The passage of the Americans With Disabilities Act (ADA) in 1990 will impact upon ILPs/ILCs, including the area of VR services. Moreover, the expanding use of assistive technology will enable an increasing number of individuals with severe disabilities to engage in gainful employment after IL and VR services. As these changes occur, it becomes evident that ILPs/ILCs are becoming an integral part of the total rehabilitation system.

Need for the Study

Many ILPs/ILCs have undergone changes in emphasis, priorities, and concepts over the years as it became clear that many individuals with severe disabilities could engage in gainful work. As a result, a number of centers have initiated services, including referral, which emphasize VR with an ultimate objective of placement in employment. Success in this area has encouraged both VR agencies and ILPs/ILCs to seek a closer working relationship in terms of vocational outcomes. Cooperative activities in the areas of supported employment and transition to work, as well as projects with special populations (e.g., traumatic brain injury among others) have shown that coordinated efforts can be mutually beneficial.

Purpose of the Study

The IRI Prime Study Group has attempted to look at VR services in ILPs/ILCs from a number of viewpoints. The Prime Study Group has reviewed the history, philosophy, and development of the disability movement and defined relevant terms. Specific attention is given to the provision of VR services through ILPs/ILCs and the impact of these services. Implications for both IL and VR are analyzed. Current

practices of ILPs/ILCs providing employment services are reviewed through a research project in this area and through a discussion of model programs which could be replicated by other organizations. The document concludes with a discussion of visions and recommendations compiled from interviews with a number of prominent individuals in the field, and a new rehabilitation paradigm is proposed.

Charges to the IRI Prime Study Group

The following charges were given to the IRI Prime Study Group related to the development of the study:

1. To develop a resource document that will address the common goals and the differences between VR and ILPs/ILCs in the provision of services to people with severe disabilities.

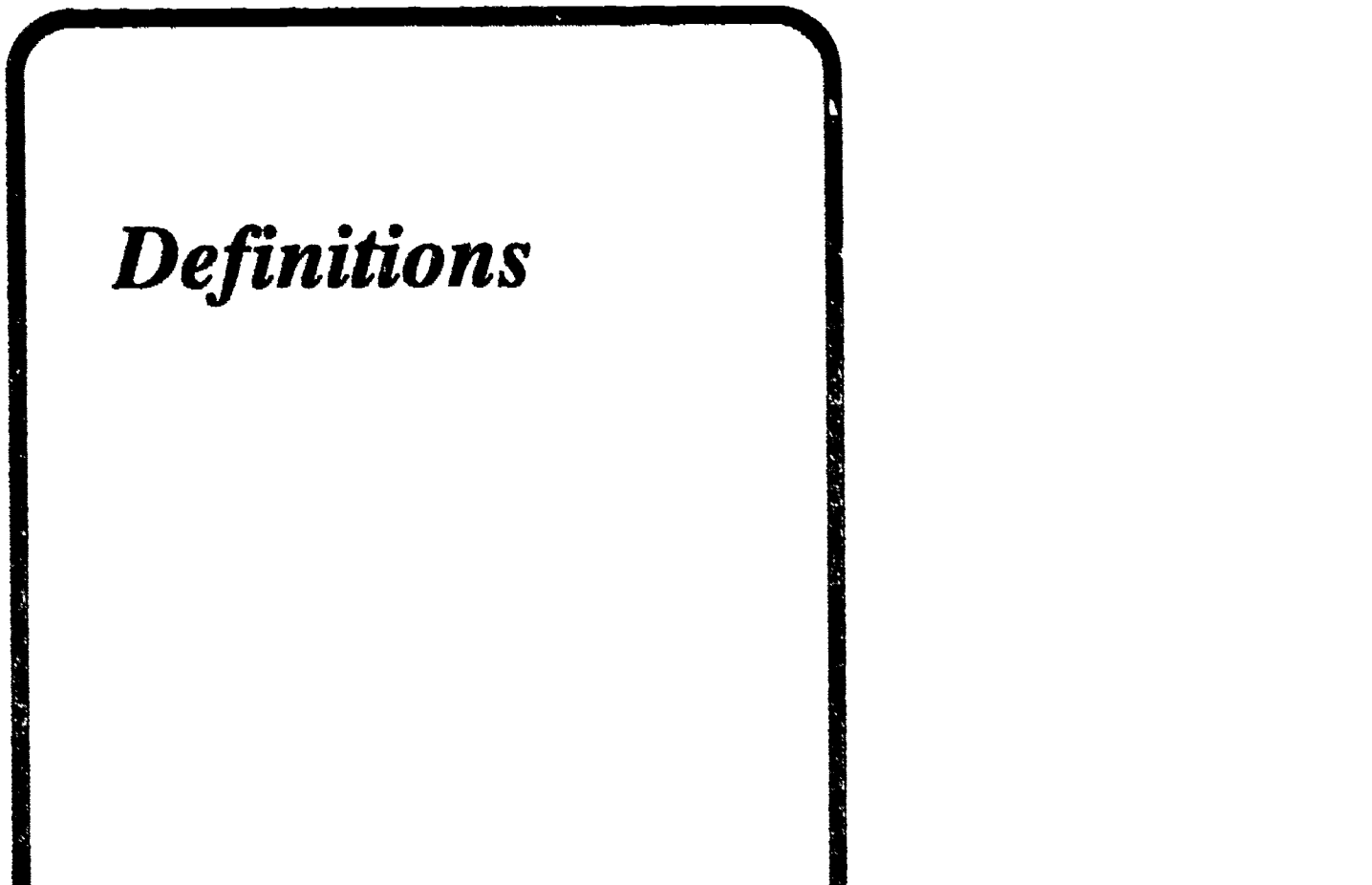
2. To develop a manual that will serve as a resource for staff development personnel, rehabilitation educators, program administrators, and VR and IL practitioners.

3. To present model programs of joint efforts of VR and ILPs/ILCs in the provision of comprehensive services to persons with severe disabilities and to review current practices, barriers, and factors that support and impede collaborative efforts.

Conclusions

The IL movement has made a definite impact not only on individuals with severe disabilities but on the total rehabilitation field. Both VR and ILPs/ILCs are moving toward a more coordinated and comprehensive effort to provide more and better services to persons with disabilities. If this promising approach is to reach fruition, it is obvious that changes must continue to take place, not only with VR services in ILPs/ILCs, but at the legislative and policymaking levels. Adequate funding and resources to insure that needed services are provided will also be prerequisite.

Definitions



Chapter Two

DEFINITIONS

I. OBJECTIVES:

A. To provide operational definitions of key concepts, organizations, and agencies

B. To identify statutory definitions which are relevant to the operational definitions

C. To explain why the operational definitions have been formulated as they have, and why they differ from the relevant statutory definitions

II. SUMMARY:

This chapter provides operational definitions of terms from the vocational rehabilitation (VR) agencies and independent living (IL) programs and also from the broader disability rights and IL movements. It presents the following definitions, each including a discussion of relevant statutory language and the rationale for the definition:

III. DISCUSSION:

To deal with VR services in independent living centers and programs (ILCs/ILPs) requires reference to the language of both areas, as well as that of the broader disability rights and IL movements. Although it is still undergoing change, there is sub-stantial agreement on common language that has evolved in the VR program. As a newer and still emerging area, the IL program is moving toward

development of its own common language. Within the broad scope of the full disability rights and IL movements, there is wide diversity of language, although substantial agreement has been achieved concerning some key terms.

This chapter provides definitions of terms from all four areas, to clarify the purposes and themes of the document. The definitions are provided as guides for consideration in the development and implementation of VR/IL programs and services. Although based upon statutory and regulatory provisions, they go beyond the statutory language to provide added explanation of the essential nature of selected concepts, programs, and services.

Included are updates of the IL definitions contained in the Seventh Institute on Rehabilitation Issues (IRI) (Rice, 1980, pp. 2-8), Implementation of Independent Living Programs in Rehabilitation. These versions have been modified as needed to better reflect the general consensus which has developed in recent years.

Compared to other disability services programs, the VR program is noted for its clarity of purpose and consistency of practice. IL programs, in contrast, present a diversity of services adapted to meet the unique needs of consumers in the local communities. The definitions attempt to characterize essential elements of commonality between the VR and IL programs. They also provide a basis for sorting out the respective roles and responsibilities of the various agencies and organizations involved in the rehabilitation system.

Terms

Disability Rights Movement

> **Definition:** The historic and long-term drive by people with disabilities to be empowered with the rights of self-determination and control of their own lives, to become integrated as active, productive, and respected members of their families and communities, and to receive needed services.

A central theme of this document is that neither the VR and IL programs nor the rehabilitation system can be assessed in isolation from the broader disability rights movement. The drive of people with disabilities for independence and integration sets the long-term context within which all rehabilitation services (as well as all other disability services) must be understood. The definition of the disability rights movement provides a general reference to that long-term context, which is described in more detail in the next chapter.

Independent Living

> **Definition:** The right of people with disabilities to control and direct their own lives and to participate actively in society.
>
> To *control and direct* one's life means making cultural and life style

> choices among options that minimize reliance on others in decision-making and in performance of everyday activities, limited only in the same ways that people without disabilities are limited. It means exercising the greatest possible degree of choice about where you live, with whom to live, how to live, and how to use time. This includes taking risks and having the right to succeed or fail. It also includes taking responsibility for one's decisions and actions.
>
> To *participate actively* in society means having opportunities to fulfill a range of social roles. These include working, owning a home, raising a family, engaging in leisure and recreational activities, and participating to the extent one chooses in all aspects of community life. This includes asserting one's rights and fulfilling one's responsibilities as a citizen.

In the Rehabilitation Act, as amended (1986), IL is explained as "the ability of an individual with handicaps to live independently and function within his/her family and community and, if appropriate, secure and maintain appropriate employment" (Title VII, Section 702[b]).

The Seventh IRI (Rice, 1980), Implementation of Independent Living Programs in Rehabilitation, using the sources identified defined IL as follows:

> The ability of the severely disabled person to participate actively in society: to work; to own a home; to raise a family; and, in general, to participate to the fullest extent possible in normal day-to-day activities (Fifth IRI, 1978). (p. 6)
>
> Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs; participating in day-to-day life in the community; fulfilling a range of social roles; and making decisions that lead to self-determination and the minimization of psychological or physical dependence upon others. Independence is a relative concept, which may be defined personally by each individual (ILRU, 1979). (p. 6)

A poster in the Ann Arbor Center on Independent Living in Michigan defines IL as:

> Controlling and directing your own life; taking risks and being allowed to succeed and fail; having opportunities to participate in all aspects of community life; making decisions and taking responsibility for your actions; exercising the greatest degree of choice about where you live, with whom you live, and how you live; asserting your rights and responsibilities as first-class citizens.

In an ILRU pamphlet entitled, "An Orientation to Independent Living Centers," Richard Laurel and Quentin Smith (1987) provided this very direct definition:

What is independent living? Essentially, it is living just like everyone else, having opportunities to make decisions that affect one's life, able to pursue activities of one's own choosing, limited only in the same ways that one's nondisabled neighbors are limited.

Independent living should not be defined in terms of living on one's own, being employed in a job fitting one's capacities and interests, or having an active social life. These are aspects of living independently. Independent living has to do with self-determination. It is having the right *and* the opportunity to pursue a course of action. And, it is having the freedom to fail and to learn from one's failures, just as nondisabled people do.

There are, of course, individuals who have certain mental impairments which may affect their abilities to make complicated decisions or pursue complex activities. For these individuals, independent living means having every opportunity to be as self-sufficient as possible.

Independent living. It isn't easy, and it can be risky. But, millions of people with disabilities rate it higher than a life of dependency and narrow opportunities and unfulfilled expectations. (pp. 2-3)

The operational definition includes elements from all of these definitions. It begins by identifying IL as a "right" which reflects the IL movement's sense that this is not merely a concept, but rather a condition that should be socially and legally enforceable. The concepts of both "control and direction" and "participation" are included, to clarify that IL involves both decision-making and action. Recognition is given to the limitations that affect all people (both those with disabilities and those without) in order to acknowledge the natural interdependence of human beings and avert any implication that an unrealistic absolute independence is being sought. Several aspects of decision-making are highlighted to assure a balanced and comprehensive perspective, including the concepts of choice, acceptable options, risk-taking, and acceptance of responsibility. Finally, several aspects of participation are similarly highlighted for balance and comprehensiveness, including reference to employment, commercial, family, recreational, community, and citizenship roles.

Independent Living Centers or Centers for Independent Living

> **Definition:** Consumer-controlled, community-based advocacy and service organizations designed and operated within their local communities by people with disabilities to provide an array of community development and consumer se ices. Their mission is to empower people with all types of disabilities to live more

independently and have control over their lives. They constitute the primary advocacy and service delivery system for the IL movement.

Consumer controlled means that the organization's governing board includes a majority of people with disabilities, and that emphasis is placed on consumer control of advocacy and service objectives.

Community development services are provided by ILCs to increase local options available to people with disabilities. Services include community needs assessment, interagency coordination, systems advocacy for needed community change (especially the development of needed services resources), technical assistance, public information and education, outreach, and community initiatives.

Direct consumer services are provided by ILCs to empower people with disabilities to increase their self-determination, achieve personal goals, and become more effective members of their families and communities. Included are the core services of information and referral, peer consultation, individual advocacy, and skills training, as well as other services determined to be locally appropriate.

All types of disabilities means that the ILCs advocate on behalf of, and offer their services to, all persons with disabilities regardless of diagnostic categories.

Primary service delivery system means that the ILCs are the primary agents that represent and promote the IL movement and its philosophy.

A detailed *operational definition* of ILCs is provided by the "Standards for Independent Living Centers" as approved by the National Council on Disability in accord with the 1984 Amendments to the Rehabilitation Act of 1973.

Title VII, Part B, Section 711(c)(2), of the Rehabilitation Act, as amended in 1984 (P.L. 98-221), defines ILCs as facilities which,

> ...offer individuals with handicaps a combination of independent living services, including as appropriate:
> (A) intake counseling to determine the client's need for specific rehabilitation services;
> (B) referral and counseling services with respect to attendant care;
> (C) counseling and advocacy services with respect to legal and economic rights and benefits;
> (D) independent living skills, counseling, and training, including such programs as training in the maintenance of necessary equipment and in job-seeking skills, counseling on therapy needs and programs, and special programs for the blind and deaf;
> (E) housing, recreation, and transportation referral and assistance;

(F) surveys, directories, and other activities to identify appropriate housing, recreational opportunities, and accessible transportation, and other support services;
(G) health maintenance programs;
(H) peer counseling;
(I) community group living arrangements;
(J) education and training necessary for living in the community and participating in community activities;
(K) individual and group social and recreational services;
(L) other programs designed to provide resources, training, counseling, services, or other assistance of substantial benefit in promoting the independence, productivity, and quality of life of individuals with handicaps;
(M) attendant care and training or personnel to provide such care; and
(N) such other services as may be necessary and not inconsistent with the provisions of this title;

ILCs have evolved several characteristics that separate them from more traditional service delivery programs. The Center for Resource Management (1988) identifies these unique characteristics as:

- Consumer control at the policy level of a center's operations—Board of Directors comprised of a majority of persons with disabilities;
- Extensive representation of persons with disabilities at the administrative and service delivery staffing level;
- Emphasis on services to a cross-disability consumer population;
- Emphasis on consumer control of service objectives and on peer role modeling; and
- Provision of (the) such core services as information and referral, peer counseling, independent living skills training, individual advocacy and community advocacy. (p. 12)

It should also be noted that the last descriptor lists the core services which are now in the National Standards as approved by the National Council on Disabilities in accord with the 1984 Amendments to the Rehabilitation Act. They were described as follows by The Center for Resource Management in collaboration with the National Council on Independent Living in the publication, The Independent Living Services Model (Center for Resource Management and National Council, 1988):

1. Information and Referral

Access to information and referral services is essential for people with disabilities. In addition to varied types of direct services, individuals need information on options, resources, and the issues that influence their abilities to achieve independent life-styles. Referral assistance is also essential since achieving independence most often requires involvement of a variety of agencies and community organizations.

Information and referral services are also provided to other service providers and the community at large. This assistance is instrumental in increasing public awareness of disability issues and knowledge of the service options and resources available to people with disabilities from the center and the community.

2. Advocacy

Many persons in the independent living movement have described the advocacy services provided by ILCs as the "cornerstone" of an IL center. It is the service that truly separates centers from other community based programs for persons with disabilities.

Independent living centers provide advocacy support to individual consumers as well as group advocacy. The central themes that run through the advocacy assistance are consumer control and self-reliance. Reflecting such basic tenets as the right to control one's own life and to make choices, this core service area involves a process that empowers consumers to act on their own behalf and resist accepted norms of dependency.

3. Peer Counseling

Emphasizing the direct involvement of persons with disabilities as role models in the service process, peer counseling has also been described as a cornerstone of independent living services to consumers. A basic premise of peer counseling is that, by virtue of their disability-related experience, people with disabilities are uniquely qualified to assist their own peers. Through this core service area, a peer counselor or peer advocate who has achieved a desired level of independence and community integration shares knowledge and experiences with a consumer. The process facilitates consumer awareness of independent living options and how to approach certain situations and seeks to motivate confidence in overcoming external barriers that inhibit independence.

4. Independent Living Skills Training

Skills development is an important feature of achieving or enhancing an independent life-style. The national evaluation study determined that almost all Part B funded independent living centers offer some type of skills training, but variation exists in who conducts the training, range of skill areas covered, where training occurs, and extent to which the training is formalized.

Some centers view skill development as a key element of other core services such as peer counseling and advocacy rather than as a discrete service component. In centers where skills training is a separate service, it may be provided on a one-to-one basis, through groups to address the

common needs of consumers, or both.

There is a trend for centers that offer structured types of skills training to develop formal written curricula or training sequences, especially if they offer training to groups.

Examples of skill areas offered are:

- Managing personal assistance services
- Carrying out personal care and daily living activities
- Using message relay services
- Managing personal finances

There are many other services that ILCs provide. These core services, however, are not necessary for an ILC to meet the requirements of the National Standards.

The operational definition proposed for ILCs/CILs summarizes the major points contained in the above references, as well as in the National Standards. Some of the points merit further explanation.

Consumer control is perceived as the central driving force for the IL movement.

The *community-based* nature of the ILCs is emphasized because community-based services and activities are pervasive themes in the IL movement. "Community" has traditionally been interpreted in terms of all people within a designated geographic area. Some would argue that the term can also be interpreted in a nontraditional manner to apply to persons joined into a community on a basis other than mere geography such as a shared culture. The IL movement is currently working to resolve issues concerning how best to deal with different cultural communities including cultures of differing national or ethnic origins (e.g., Hispanic, African-American, Asian) as well as those related to disability (e.g., blindness, deafness). Resolution of these issues is not, however, necessary for the purposes of this document. The community-based nature of the ILCs is seen to be equally important, no matter how one defines or interprets the community.

Community development services have been given emphasis because they, in conjunction with the consumer control principles, are what distinguish ILCs from other service providers. The ILCs are participatory change agents, working within their individual communities to effect needed change. In order to increase community options for people with disabilities, they work to bring about attitudinal change and political action. Their community development services are probably best characterized by their systems advocacy and public information/education activities.

All types of disabilities are emphasized since the cross-disability emphasis is an essential element of the IL movement. There is much discussion and debate concerning application of this principle to ILCs. For the purposes of this document, it is deemed

essential that the ILCs perceive themselves as part of the long-term, broad-based disability rights movement. This does not preclude appropriate outreach and targeting of services, nor does it rule out nontraditional definitions of community. It does, however, mean that the community-based nature of an ILC gives it responsibility for representing the needs of all people with disabilities within that community (however it is defined), and suggests that the ILC cannot exclude segments of the community based upon diagnostic categories or groupings.

The ILCs are defined as the *primary advocacy and service delivery system* for the IL movement in recognition of their legitimate stewardship of the philosophy and energy of that movement.

The **"Standards for Independent Living Centers"** are emphasized because, once approved by the National Council on Disability in accord with the 1984 Amendments to the Rehabilitation Act, they became the basic national reference for what an ILC is and what it should do.

Independent Living Movement

> **Definition:** The civil rights movement for people with disabilities promotes the philosophy that people with disabilities have the right to control their own lives and have access to the same options as people without disabilities. This philosophy is based upon the concepts of disability self-esteem and personal value, consumer control and self-determination, self-help and peer support, and political and social activism.
>
> *Disability self-esteem and personal value* means that disability is a natural part of the human experience which does not in any way diminish the individual's right to a sense of personal importance and self-respect.
>
> *Consumer control and self-determination* means that people with disabilities should be individually empowered to make decisions about their own destinies, and collectively empowered to make decisions about programs and services to meet their needs.
>
> *Self-help and peer support* means that people with disabilities should be perceived as the solution, not the problem. People with disabilities should be individually enabled to obtain the information, resources, and skills they need to resolve their own problems, and should join together to collectively assist each other.
>
> *Political and social activism* means that people with disabilities should individually and collectively work to obtain and assure their rights through active involvement in political and social processes.

The IL movement is one of the newest manifestations of the historic and long-term disability rights movement. As will be discussed in Chapter 3, the IL movement

formed during the 1960s and 1970s. During these years, people with disabilities and their supporters developed a civil rights movement for people with disabilities. This movement was inspired and influenced strongly by the civil rights activities by Black Americans, and also by related movements such as women's rights, deinstitutionalization, consumerism, self-help initiatives, and movement from the medical model of service delivery.

The IL movement has been examined in a number of articles and reports, such as that by Gerben DeJong (1979), The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research. The movement's context and history are discussed in Chapter 3.

A definition of the IL movement is included here because it has inspired and served as the impetus for the formation of ILCs/ILPs. An understanding of the ILCs in particular, as well as other programs that explicitly identify themselves with the IL movement, requires a commensurate understanding of the movement. Their missions and purposes go beyond the simple provision of services, to encompass the broader social and political intents of the philosophy, as detailed in this definition.

Independent Living Program

> **Definition**: A service program which has substantial consumer involvement, identifies with the IL movement, and provides directly, or coordinates indirectly through referral, services necessary to assist people with disabilities to live more independently and have control over their lives.[1]
>
> *Substantial consumer involvement* means that the program accepts and promotes the central IL principle of consumer control.
>
> *Identifies with the IL movement* means that the program explicitly relates to the IL movement and promotes the principles of that movement.

During the early part of the IL movement, "ILP" was defined in a generic manner. Sometimes it was essentially the same thing as an "ILC," and other times it was the more general category of which the ILC was a specialized example.

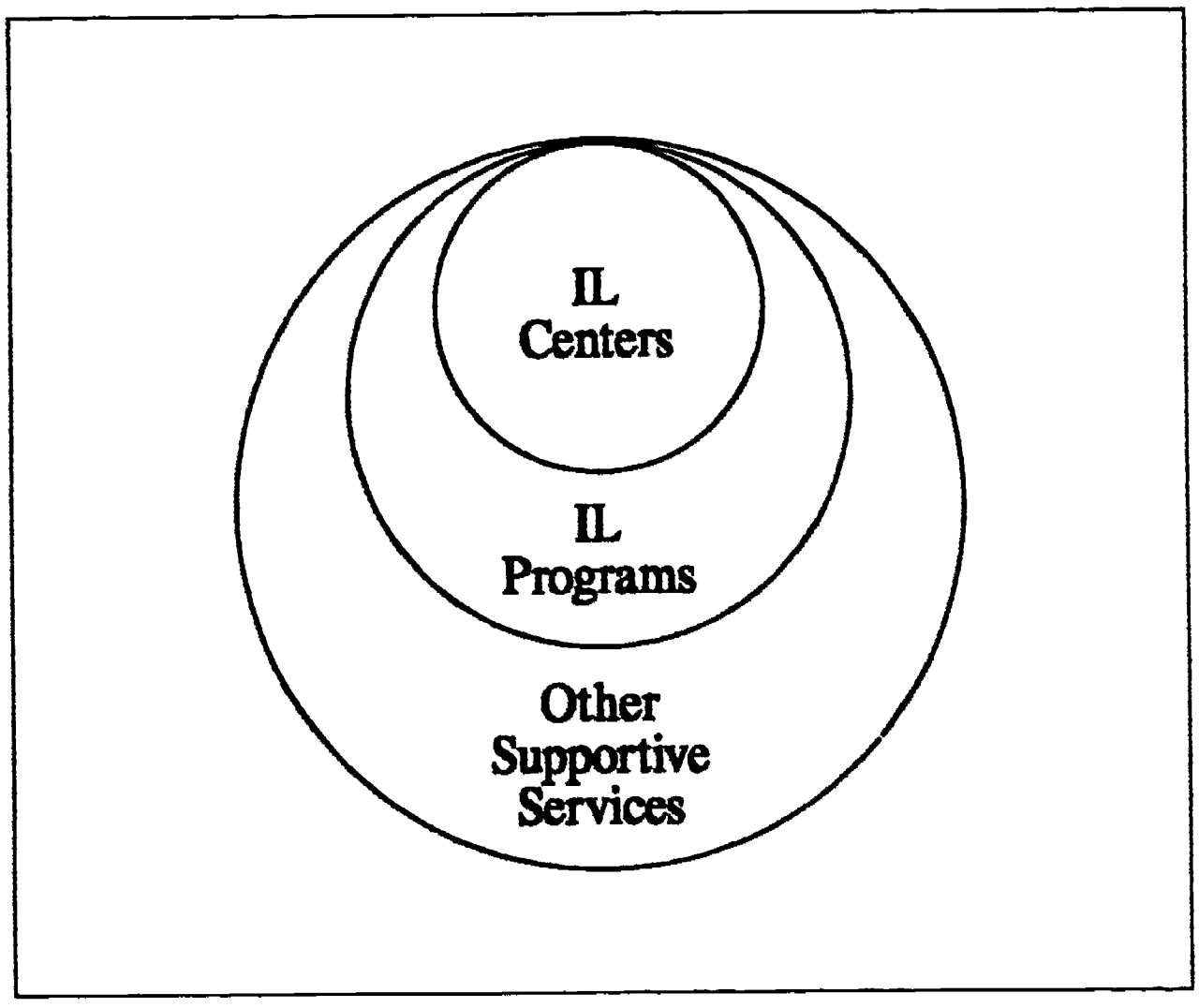
During recent years, a general agreement has been growing that there are subtle differences between ILCs and ILPs. Consensus on defining these differences has, however, been most difficult to achieve. One common definition of an ILP focuses upon who receives services and the type of administrative structure through which services are provided. Under this approach, an ILP may be one which provides services to a specific group or type of disability constituency (rather than to the cross-disability clientele of an ILC). Or, although accepting the principles of consumer involvement, it provides many other types of services as well as IL services (rather than concentrating on IL services, as does an ILC). This latter type of agency is sometimes described as an

[1] The definition refers primarily to programs which share the philosophy and approach of the ILCs but which do not meet some of the requirements to qualify as ILCs.

umbrella organization, in that IL is not the only function or service it provides.

For the purposes of this document, it is helpful to distinguish ILCs from ILPs, and then to distinguish both from other supportive services. In brief, this approach sees the ILCs as consumer-controlled, community-based IL organizations; the ILPs as other service programs committed to the IL movement and philosophy; and, other supportive services as those additional disability and human services which are needed to achieve IL purposes. These relationships can be diagrammed (see Figure 1):

Figure 1



Independent Living Rehabilitation (ILR) Services

> **Definition:** Professional rehabilitation services designed and provided through a formalized rehabilitation program to enhance the ability of persons with disabilities to live independently, to function within the family and community, and if appropriate, to secure and maintain appropriate employment.[2]
>
> *Professional rehabilitation services* means services which are designed and provided in accord with the principles and processes of the rehabilitation profession.
>
> *Formalized rehabilitation program* means a structured service program which is organized around the principles and processes of the rehabilitation profession and which employs skilled, professional rehabilitation counselors.

The Seventh IRI (Rice, 1980), Introduction to Independent Living Rehabilitation Services, offered the following definitions of ILR services:

> Includes a broad scope of service which may be designed to assist an individual to function more independently in family and community living activities and where appropriate, to assist the individual to engage or continue in employment. (p. 7)
>
> ILR refers to a formalized program of services designed to assist severely handicapped individuals adjust, function, and live as independently as possible within the community of their choice. (p. 7)

Title VII, Part A, Section 702(b), of the Rehabilitation Act, as amended, sets the following definition of "comprehensive services for independent living:"

> ...any appropriate vocational rehabilitation service (as defined under Title I of this Act) and any other service that will enhance the ability of an individual with handicaps to live independently and function within his family and community and, if appropriate, secure and maintain appropriate employment. Such services may include any of the following: counseling services, including psychological, psychotherapeutic, and related services; housing incidental to the purpose of this section (including appropriate accommodations to and modification of any space to serve individuals with handicaps); appropriate job placement services; transportation; attendant care; physical rehabilitation; therapeutic treatment; needed prostheses and other appliances and devices; health maintenance; recreational services;

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[2] Although this definition can include others, it refers primarily to professional rehabilitation services programs operated in accord with the provisions of Title VII, Part A of the Rehabilitation Act, as amended.

> services for children of preschool age, including physical therapy, development of language and communication skills, and child development services; and appropriate preventive services to decrease the needs of individuals assisted under the program for similar services in the future.

An interesting perspective on ILR services was offered by Gerben DeJong (1979) in his analysis of the IL movement:

> ...vocational rehabilitation professionals, as reflected in the legislation reviewed here [the 1973 Rehabilitation Act, as amended], have a different conception of independent living than do their consumer counterparts in the movement for independent living. For many vocational rehabilitation professionals, independent living services are for those for whom a vocational goal is thought to be impossible. Independent living is seen as an alternative to the vocational goal—thus, the term "independent living rehabilitation." Independent living rehabilitation refers to those medical and social services that enable a disabled person to live in the community short of being gainfully employed. From this perspective, independent living and rehabilitation are seen as competing policy goals. Throughout the history of the legislative debate on independent living, there has been the fear that independent living would dilute the specificity of the vocational outcomes. Some professionals feared that independent living services would result in the same charges of nonaccountability often levied against more ill-defined social services such as those administered under Title XX of the Social Security Act. (pp. 20-21)

The need for the term "independent living rehabilitation services," and its meaning are matters of some controversy. An operational definition has been included in this document because the term is believed useful in addressing differences in the respective roles and responsibilities of state rehabilitation agencies and ILCs/ILPs.

The definition is based generally upon the statutory provisions, but also takes into account the context within which ILR services are designed and provided. In general, ILR services are perceived to be provided in accord with the defined rehabilitation process, and do not necessarily involve the peer support and advocacy components which are so integral to the ILCs. Accordingly, the operational definition of ILR services reflects the provision of "professional" rehabilitation services for the achievement of increased independent functioning (i.e., nonvocational) outcomes and, if appropriate, to secure and maintain employment. In this way, ILR services are (a) placed within the context of the traditional rehabilitation process (and thereby distinguished from the services of an ILC), (b) focused primarily on IL needs (and thereby distinguished from VR services), but also (c) linked to the achievement, if appropriate, of vocational outcomes (and thereby interlinked with both VR and ILC services).

Rehabilitation System

Definition: The national system of disability services established under the Federal Rehabilitation Act, as amended, and related programs. The system includes the following major program areas:

Vocational Rehabilitation ..... Title I

Research and Training (R&T) and the
National Institute on Disability and
Rehabilitation Research
(NIDRR) ..... Title II

Rehabilitation Facilities,
Special Projects and
Supplementary Services ..... Title III

National Council on Disability ..... Title IV

Accessibility, Equal Opportunity,
and Nondiscrimination for
People with Handicaps ..... Title V

Community Employment ..... Title VI

Independent Living ..... Title VII

It also includes related programs such as those authorized by the Education for All Handicapped Children Act of 1975, the Developmentally Disabled Assistance and Bill of Rights Act, The Social Security Act, and the Americans with Disabilities Act of 1990.

The national rehabilitation system traces its direct origins to 1920 under the Smith-Fess Act (P.L. 66-236). Since that time, it has expanded greatly in both scope and impact, as have the major programs with which it interacts. Chapter 3 provides further insight into that process.

The term "rehabilitation system" is frequently used in reference primarily to the VR program established under Title I of the Rehabilitation Act, as amended. However, for purposes of this document, it is important that the rehabilitation system denote the *full* range of programs for people with disabilities that have been established under the Rehabilitation Act, as amended, and other related legislation. Indeed, viewed in terms of its total impact upon Americans with disabilities, those served under Title I represent only a portion of the population directly impacted by the Act. The operational definition emphasizes the scope and the multipart system which the Rehabilitation Act, as amended, has established, and includes the other major systems with which it interacts.

Vocational Rehabilitation Services (VRS)

> **Definition:** Professional rehabilitation services designed and provided through a formalized rehabilitation program to assist a person with a disability to become employable.[3]
>
> *Professional rehabilitation services* means services which are designed and provided in accord with the principles and processes of the rehabilitation profession.
>
> *Formalized rehabilitation program* means a structured services program which is organized around the principles and processes of the rehabilitation profession and which employs skilled, professional rehabilitation counselors.
>
> *To assist a person ... to become employable* means to enable the individual to enter, retain, or reenter full or part-time employment, which is consistent with the capacities of the individual within the competitive labor market or other appropriate work setting.

Title I, Section 103, of the Rehabilitation Act, as amended, defines vocational rehabilitation services as follows:

> (a)...any goods or services necessary to render an individual with handicaps employable, including, but not limited to, the following:
> (1) evaluation of rehabilitation potential, including diagnostic and related services, incidental to the determination of eligibility for, and the nature and scope of services to be provided, including, where appropriate, evaluation by personnel skilled in rehabilitation engineering technology, examination by a physician skilled in the diagnosis and treatment of mental or emotional disorders, or by a licensed psychologist in accordance with State laws and regulations, or both;
> (2) counseling, guidance, referral, and placement services for individuals with handicaps, including follow-up, follow-along, and specific postemployment services necessary to assist such individuals maintain or regain employment, and other services designed to help individuals with handicaps secure needed services from other agencies, where such services are not available under this Act;
> (3) vocational and other training services for individuals with handicaps, which shall include personal and vocational adjustment, books, or other training materials, and services to the families of such individuals as are necessary to the adjustment or

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[3] Although this definition can include others, it refers primarily to vocational rehabilitation programs operated under the authority of the State Rehabilitation Agency in accord with the provisions of Title I of the Rehabilitation Act, as amended.

rehabilitation of such individuals: provided, that no training services in institutions of higher education shall be paid for with funds under this title unless maximum efforts have been made to secure grant assistance, in whole or in part, from other sources to pay for such training;

(4) physical and mental restoration services, including, but not limited to,

(a) corrective surgery or therapeutic treatment necessary to correct or substantially modify a physical or mental condition which is stable or slowly progressive and constitutes a substantial handicap to employment, but is of such nature that such correction or modification may reasonably be expected to eliminate or substantially reduce the handicap within a reasonable length of time,

(b) necessary hospitalization in connection with surgery or treatment,

(c) prosthetic and orthotic devices,

(d) eyeglasses and visual services as prescribed by a physician skilled in the diseases of the eye or by an optometrist, whichever the individual may select,

(e) special services (including transplantation and dialysis), artificial kidneys, and supplies necessary for the treatment of individuals suffering from end-stage renal disease, and

(f) diagnosis and treatment for mental and emotional disorders by a physician or licensed psychologist in accordance with State licensure laws;

(5) maintenance, not exceeding the estimated cost of subsistence, during rehabilitation;

(6) interpreter services for deaf individuals, and reader services for those individuals determined to be blind after an examination by a physician skilled in the disease of the eye or by an optometrist, whichever the individual may select;

(7) recruitment and training services for individuals with handicaps to provide them with new employment opportunities in the fields of rehabilitation, health, welfare, public safety, and law enforcement, and other appropriate service employment;

(8) rehabilitation teaching services and orientation and mobility services for the blind;

(9) occupational licenses, tools, equipment, and initial stocks and supplies;

(10) transportation in connection with the rendering of any vocational rehabilitation service;

(11) telecommunications, sensory, and other technological aids and devices; and

(12) rehabilitation engineering services.

(b)...Vocational rehabilitation services, when provided for the benefit of groups of individuals, may also include the following:

(1) in the case of any type of small business operated by

> individuals with the most severe handicaps the operation of which can be improved by management services and supervision provided by the State agency, the provision of such services and supervision, along or together with the acquisition by the State agency of vending facilities or other equipment and initial stocks and supplies;
> (2) the construction or establishment of public or nonprofit rehabilitation facilities and the provision of other facilities and services (including services offered at rehabilitation facilities) which promise to contribute substantially to the rehabilitation of a group of individuals but which are not related directly to the individualized rehabilitation written program of any one individual with handicaps;
> (3) the use of existing telecommunications systems (including telephone, television, satellite, radio, and other similar systems) which has the potential for substantially improving service delivery methods, and the development of appropriate programming to meet the particular needs of individuals with handicaps; and
> (4) the use of services providing recorded material for the blind and captioned films or video cassettes for the deaf.

Title I, Section 7, also defines employability:

> The term "employability," with respect to an individual, means a determination that, with the provision of vocational rehabilitation services, the individual is likely to enter or retain, as a primary objective, full-time employment, and when appropriate, part-time employment, consistent with the capacities or abilities of the individual in the competitive labor market or any other vocational outcome the Secretary may determine consistent with this Act.

The operational definition is based upon these statutory provisions, formulated in a more general manner to be similar to that used for the definition of ILR services.

In essence, the proposed operational definitions of ILR and VR services differ only in the intended outcomes of services--vocational outcomes for VR services, self-determination and more independent functioning for ILR services.

State Rehabilitation Agency

> **Definition:** The state agency designated as the sole state agency to administer, or to supervise the administration of, the state plan for vocational rehabilitation services under Title I of the Rehabilitation Act, as amended. States that have law authorizing state agencies for the blind to provide vocational rehabilitation services may identify them as the state rehabilitation agency for the blind, with separate state agencies identified as the state rehabilitation agency for other citizens. The agen-

cies designated under Title I for vocational rehabilitation services are also to be identified as the designated state agencies for the Title VII independent living programs.

Title I, Section 101, of the Rehabilitation Act, as amended, provides the following detailed provisions concerning the state rehabilitation agency:

> (1)(A) designate a state agency as the sole State agency to administer the plan, or to supervise its administration by a local agency, except that
>
> (i) where under the State's law the State Agency for the blind or other agency which provides assistance or services to the adult blind, is authorized to provide vocational rehabilitation services to such individuals, such agency may be designated as the sole State agency to administer the part of the plan under which vocational rehabilitation services are provided for the blind (or to supervise the administration of such part by a local agency) and a separate State agency may be designated as the sole State agency with respect to the rest of the State plan and
>
> (ii) the Commissioner, upon the request of a State, may authorize such agency to share funding and administrative responsibility with another agency of the State or with a local agency in order to permit such agencies to carry out a joint program to provide services to individuals with handicaps, and may waive compliance with respect to vocational rehabilitation services furnished under such programs with the requirement of clause (4) of this subsection that the plan be in effect in all political subdivisions of that State;
>
> (B) provide that the State agency so designated to administer or supervise the administration of the State plan, or (if there are two State Agencies designated under clause (A) of this clause) to supervise or administer the part of the State plan that does not relate to services for the blind, shall be
>
> (i) a State agency primarily concerned with vocational rehabilitation, or vocational and other rehabilitation, of individuals with handicaps,
>
> (ii) the State agency administering or supervising the administration of education or vocational education in the State, or
>
> (iii) a State agency which includes at least two other major organizational units each of which administers one or more of the major public education, public health, public welfare, or labor programs of the State;
>
> (2) provide, except in the case of agencies described in clause (1)(B)(i)—
>
> (A) that the State agency designated pursuant to paragraph (1) (or each State agency if two are so designated) shall include a vocational rehabilitation bureau, division, or other organizational unit which
>
> (i) is primarily concerned with vocational rehabilitation, or vocational and other rehabilitation, of individuals with

handicaps, and is responsible for the vocational rehabilitation program of such State agency,
(ii) has a full-time director, and
(iii) has a staff employed on such rehabilitation work of such organizational unit all or substantially all of whom are employed full time on such work; and

(B)(i) that such unit shall be located at an organizational level and shall have an organizational status within such State agency comparable to that of other major organizational units of such agency, or

(ii) in the case of an agency described in clause (1)(B)(ii), either that such unit shall be so located and have such status, or that the director of such unit shall be the executive officer of such State agency; except that, in the case of a State which has designated only one State agency pursuant to clause (1) of this subsection, such State may, if it so desires, assign responsibility for the part of the plan under which vocational rehabilitation services are provided for the blind to one organizational unit of such agency, and assign responsibility for the rest of the plan to another organizational unit of such agency, with the provisions of this clause applying separately to each of such units;

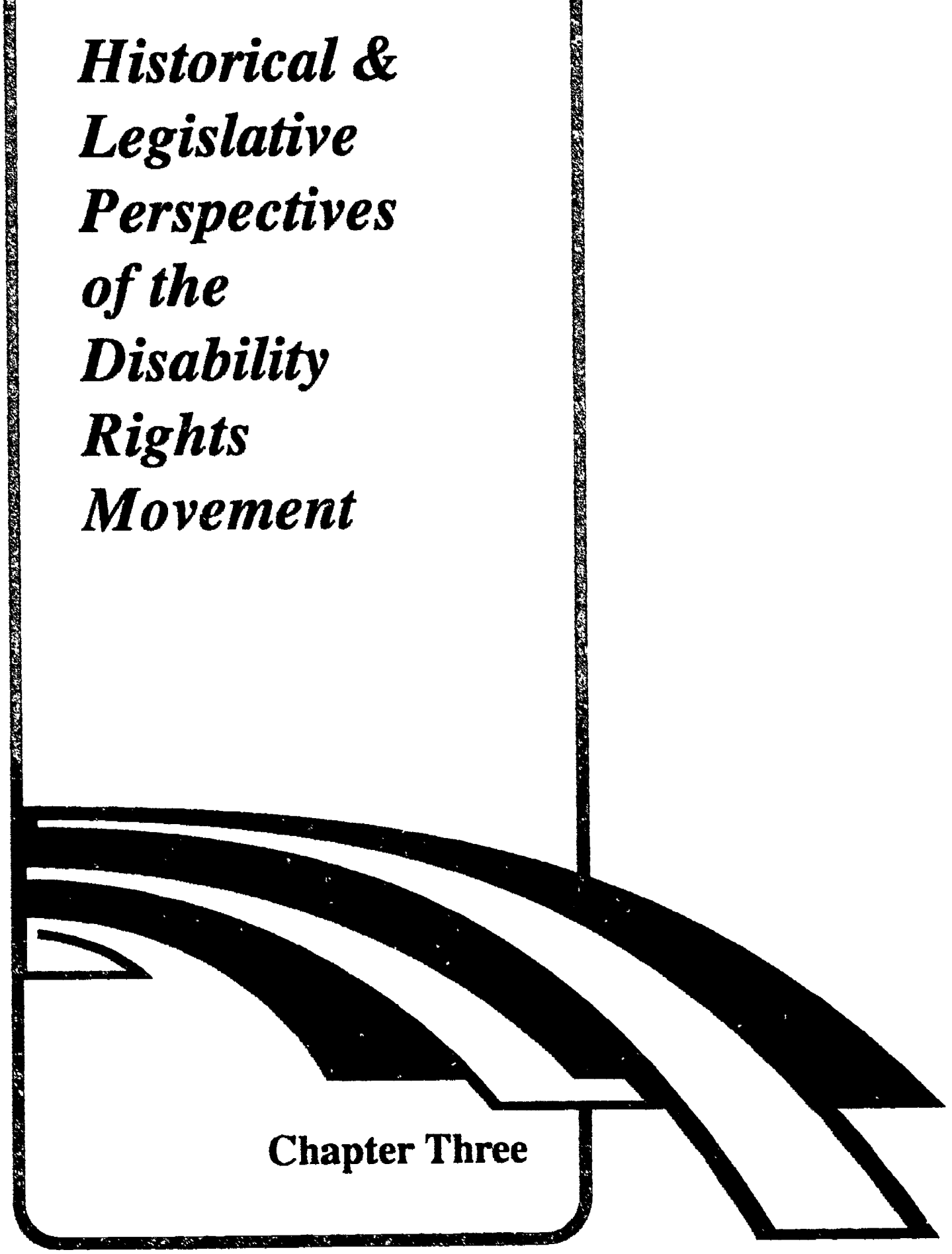
Title VII, Section 705(a)(1), of the Rehabilitation Act, as amended, refers to the Title I provisions, directing that each Title VII state plan shall:

...designate the designated State unit of such state as the agency to administer the programs funded under this part;

The operational definition is based upon these statutory provisions. Of particular significance is that it establishes clear administrative and leadership responsibilities for the rehabilitation system. As respective roles and responsibilities are negotiated among VR agencies and ILCs/ILPs, the state rehabilitation agency needs to give attention to how the various parts of the rehabilitation system fit together.

Added mention is warranted for the 22 states that have separate state rehabilitation agencies for the blind. Reaching agreement concerning administrative and leadership responsibilities under these circumstances can be especially difficult. Since each has two state rehabilitation agencies and related service delivery systems, it may operationally have two complete rehabilitation systems. Yet, the promise of the Rehabilitation Act, as amended, is a unified, comprehensive rehabilitation system. This requires collaborative administrative and program leadership between the two state rehabilitation agencies.

Historical & Legislative Perspectives of the Disability Rights Movement



Chapter Three

HISTORICAL AND LEGISLATIVE PERSPECTIVES OF THE DISABILITY RIGHTS MOVEMENT

I. OBJECTIVES:

A. To describe the nature of the disability rights movement and its relation to the national rehabilitation system

B. To provide a historical overview of the evolution of the national rehabilitation system, including the development of vocational rehabilitation (VR) and independent living (IL) services

C. To identify specific legislative and statutory provisions which define or influence operations of the national rehabilitation system, including those which make VR and IL integral parts of the system

D. To describe the nature of the IL philosophy, movement, and services (including the delivery system of independent living centers and programs [ILCs/ILPs] and their place within the national rehabilitation system)

II. SUMMARY:

The disability rights movement has traveled far, from an early belief that disability was punishment to the current broad-based drive for self-determination, independence, and community integration. One result of the disability rights movement has been creation of the national rehabilitation system. That system began with a narrow focus upon employment, which has gradually broadened to include a wide range of rights and services for people with disabilities.

Rehabilitation agencies since the initial Vocational Rehabilitation Act of 1920 (Smith-Fess Act, P.L. 66-236) have provided IL services of varying degrees to persons with severe disabilities. The civil rights movement helped launch the IL movement as a recognized social initiative during the early 1970s, at the same time that the Vocational Rehabilitation Act was becoming the Rehabilitation Act. The IL movement focused on civil rights and well-being of people with disabilities, based on the philosophy that they have the right to control their own lives and have access to the same options as others. It seeks to empower people with disabilities to participate fully in the affairs and benefits of society through provision of a broad range of information, advocacy, community development, and skills training services.

The IL movement helped bring about passage of Title VII which added ILR services and ILCs to the Federal Rehabilitation Act (1978 Amendments). The framework was thus established for IL services and their holistic, empowerment emphases to become integral parts of the nation's rehabilitation system. The current challenge is to identify the specific roles that ILR services and ILCs/ILPs can appropriately play in the national rehabilitation system, and to find ways of making them full partners in that system. The results will, hopefully, include increased

consumer success in obtaining and (most importantly) maintaining employment, and in taking control and responsibility for their own lives.

This chapter will describe the broad disability rights movement and the continuing evolution of the nation's rehabilitation system, including both VR and IL services. It will highlight contributions of both the VR system and the IL movement to the establishment of civil rights for persons with disabilities. Presentation of the historical and legislative perspectives of the disability rights movement will provide important insight to the lives of all people, and will demonstrate the ability of dedicated persons—including consumers, agency/organization staff, and volunteers—to alter the perceptions of the public about disability. Finally, the need will be shown for a more consistent and active partnership between the established VR service delivery system and the evolving service delivery system of ILCs and other IL and related providers.

III. DISCUSSION:

The Disability Rights Movement—A Drive For Independence

In order to offer the reader a broad range of perspectives and resources, a variety of sources and materials have been used in addressing the objectives. Given the nature of the topics, much of what is presented has been drawn from multiple sources. Much has also been gathered from the complex history of verbal and written communications that comprise the "tradition" of the disability rights and IL movements—in which there has been widespread borrowing and restatement of themes and concepts. Effort has been made to correctly reference sources and present accurate factual information. The reader is, however, hereby alerted to the possibilities of multiple sources and versions, and apologies are offered to any participants in the movements who feel that their materials or ideas are not appropriately quoted or acknowledged.

In the current era, America is experiencing the coming-of-age of the disability rights movement. It has its reason-for-being in age-old attitudes of fear, discrimination, and pity for people with disabilities. Over time, those with disabilities have come to realize that these long-standing societal stereotypes are themselves barriers that must *and can* be overcome. Employment of people with disabilities has become widely accepted, and those employed have proven that they can be productive and participating members of society. Empowered by these successes, and by fast-growing advances in medical and assistive technology, many persons with severe disabilities are now successfully employed. A substantial consensus has been achieved that people with disabilities should have opportunities for full participation in all aspects of society, including work. This consensus, and the long-building disability rights movement, have come to fruition in the landmark civil rights legislation of the Americans with Disabilities Act (ADA). Any discussion of the role of IL services in vocational rehabilitation must be undertaken within the context of this disability rights movement.

The Early History of Persons with Disabilities—Punishment and Pity

The earliest days of persons with disabilities were filled with oppression and discrimination. In earliest recorded history, people with disabilities were often put to death. Some societies saw them as "imperfect" or "flawed" and discarded them along with other babies who were not wanted (such as those of the wrong sex). Not having modern medical and rehabilitative technology, societies with demanding lifestyles often perceived people with disabilities as nothing but potential burdens on others and likewise put them to death or let them die. The practice of allowing persons with disabilities to die at birth or at the time of accident still happens today in some cultures.

Those who lived after severe injury or survived infancy with a congenital disability were relegated to dependency and begging. Some were sold as slaves. Others, such as those with leprosy, were destined to have lives of isolation in separate communities with persons who had similar conditions. All too often, they were considered merely as objects of aversion and pity.

Many cultures saw the onset of a disabling condition as a deserved consequence of injustice or sin. The causes of disease and disability were often not obvious, although they were ever present threats to personal and community well-being. Interpreting the unknown in terms of religious and cultural beliefs led to interrelated concepts of sin and uncleanliness. Disease was thought to be inflicted upon sinners—both upon those who had departed from the straight and true and also their family (the "sins of the father being visited upon his sons"). Protection of the community and penance by the individual were enforced through cultural and religious traditions, such as that presented in the following Old Testament passage:

> The leper who has the disease shall wear torn clothes and let the hair of his head hang loose, and he shall cover his upper lip and cry, "Unclean, unclean." He shall remain unclean as long as he has the disease; he is unclean; he shall dwell alone in a habitation outside the camp.
>
> Leviticus 13.47

Yet, even in ancient times there was some thought that one might be delivered from disease and disability. The Old Testament tradition is reflected in the following passage:

> Bless the Lord, O my soul,
> and forget not all his benefits,
> who forgives all your iniquity,
> who heals all your diseases...
>
> Psalms 103.2-3

The New Testament tradition continued to develop the theme of deliverance from disease and disability and began to place more emphasis upon the healing process and less emphasis on disabilities being the result of "sin." In one passage, as Jesus and

his disciples passed a man on the street who was blind from birth, their discussion turned to the man's sins.

> And his disciples asked him, "Rabbi, who sinned, this man or his parents, that he was born blind"? Jesus answered, "It was not that this man sinned, or his parents, but that the works of God might be made manifest in him."
>
> John 9.2-3

Through ancient times, services and assistance towards independence were nonexistent—and probably inconceivable. The individuals were reactive participants in the process, given no say at all in what was to happen with their lives. Very few cultures respected the rights of persons with disabilities. History demonstrates that, with all this abuse, the desires and needs of those with the disabilities were not included in the decision-making process.

The precursor of rehabilitation facilities can be traced to a shift toward charity and benevolence in Europe during the Middle Ages. As reported by Joseph Klier, Jr. (1989):

> Many with disabilities lived in asylums or hospitals where they were given work. The most recognized and famous at the time was Quinze Vingts, a hospital established for the blind in 1254. At the end of the 16th century, St. Vincent DePaul established workshops where the aged and infirmed were given work to "enliven their spirits and ameliorate their physical condition." These were considered by most to have been the first workshops since they were the first to provide work programs designed to benefit those with disabilities. (p. 12)

With the rise of cities and the organization of urban areas, the issues of disease and disability were often addressed in terms of poverty. The Elizabethan Poor Law of 1601 addressed the "lame, impotent, old, blind, and such other among them being poor and not able to work," and expanded in time to include the provision of medical and nursing care (Rosen, 1974). The traditional approach of that era (such as in England and France) was to trust the care of such persons to the local parish or community. This even led to practices of contracting or farming out the poor to a local "practitioner" (Rosen, 1974). Those being treated continued to be excluded from the decision-making process.

Much of the care provided was based on the concept that it was needed to protect the interests of society. The concept of "charity" was also very important-often based on the belief that, "(G)race and salvation might be achieved by giving alms" (Rosen, 1974, p. 275). As a variety of hospitals and care institutions began to develop, they continued to be paternalistic in nature and to be imbued with the professional authority of the burgeoning medical science.

Not until the late 19th century and the early 20th century did the attitudes of the general public begin to change slightly. Most persons who had severe disabilities spent their lives in institutional or sheltered settings. A few of the most affluent, however,

were able to live with control over their own lives. Some notable examples were: Renoir, who strapped a paint brush to his hand and painted from his wheelchair because of his severe arthritis; Thomas Edison, who, though deaf, became the most renowned inventor of the 19th and 20th centuries; Franklin D. Roosevelt, who was paralyzed due to polio and used a wheelchair, yet became the only President in U.S. history to serve four terms in the White House. Other notable examples whose disabilities were perhaps not so well known included George Washington, Benjamin Franklin, Susan B. Anthony, Clara Barton, Sarah Bernhardt, Moshe Dayan, and John F. Kennedy.

These are but a few of the examples of persons who, despite their disabilities, became known for their contributions to society. They were, however, the exceptions and not the rule. Most individuals with disabilities continued to be relegated to lifetimes of dependency and reliance on others.

Times were, however, changing. American society intermixed traditions from its Native American beginnings, the discipline and structure of several religions, the rich variety of ethnic and cultural traditions brought by immigrants, and the strain of individualism shared by most of its citizens. Many soldiers returning from the Revolutionary and Civil Wars came home with injuries, and families that had not previously been aware of the issue were personally confronted with the problems and constraints of disability.

The post Civil War era experienced an awakening of the country's social conscience, and a national optimism that society could now deal with previously unsolvable problems. There was a virtual explosion of social movements and institutions such as women's suffrage, temperance, widows' and orphans' benefits, poor and settlement houses, and institutions for the insane. These matters were no longer left to the isolated benevolence of the family and local community, but became issues of national concern. Moving into the Twentieth Century, the country was ready for change, and the disability rights movement was stirring. The remainder of this chapter examines in more detail the resulting development of the national rehabilitation system, the establishment of a broad legislative mandate for that and other disability services programs, and evolution of the IL movement.

Before turning to those topics, it is worth noting the importance of terminology in the disability rights movement. Terms such as "sinners" and "unclean" were explicitly negative, warning others to avoid the person so designated. Throughout history, people with disabilities have been called many things, most of the terms reflecting negative or condescending attitudes. For example, an affronting term used until very recently (in fact, still used regularly in the news media!) was "crippled." It engenders an absolutely negative stereotype.

The problem of negative terminology is common within civil rights movements. As with other civil rights organizations, a significant initiative of the disability movement has been to eliminate use of negative and dependent terminology, seeking alternatives that stress dignity, respect, and independence. Interestingly, the term "handicap" is one that has been used for most of the Twentieth Century as an alternative to "disability" (which implies *not able*). It has been promoted as a more neutral term

which can be used in much the same sense as a golf handicap. The origin of this term was discovered in the late 1970s. It came from the name given those with disabilities who lived in England in the 15th and 16th century. People with disabilities would stand, sit or lie at the street corner with their caps in hand, begging. This led to their being called "hand cappers" or finally handicap or "handicappers." This points out how the same term can, over time, come to have different perceived connotations.

Although debate continues on which term most aptly describes persons with disabilities, the phraseology, "*person* with a disability" (with the word person coming first), is the nomenclature most widely accepted today. This approach does not attempt to disguise the physical or mental characteristic, but puts primary emphasis on the person. In this way, it attempts to communicate that the individual is a whole person with dignity and rights intact, regardless of the characteristics which he or she may experience.

Evolution of the National Rehabilitation System

The Twentieth Century has seen the evolution of American disability policy and the national rehabilitation system. A number of the major events in that evolution are listed below. Several of the most important events are then discussed in more detail.

IMPORTANT EVENTS IN THE DEVELOPMENT OF DISABILITY POLICY AND THE NATIONAL REHABILITATION SYSTEM

1636	Colonial law by Pilgrims at Plymouth gave benefits to disabled soldiers
1830s	Schools for the blind were established in New York, Pennsylvania, and Massachusetts
1879	"An Act to promote the Education of the Blind" provided annual funds for books and educational materials to blind children
1862	U.S. "general law" pension system was passed for soldiers disabled in the line of duty, and widows and other dependent relatives of soldiers who died in the line of duty
1865	President A. Lincoln called upon Congress & American people "...to care for him who shall have borne the battle and for his widow and his orphan..."—to become the motto of the VA
1885	First workshop financed fully from public funds was established in Oakland, California
1918	Soldier Rehabilitation Act began a national rehabilitation program

1920	Smith-Fess Act (P.L. 66-236) began program of Vocational Rehabilitation of civilians disabled in industry or otherwise
1930	Veterans Administration was established
1931	Pratt-Smoot Act established a program for the blind through the Library of Congress
1935	Social Security Act was established and first permanent authorization made for VR program
1936	Randolph-Sheppard Act authorized blind vending stands in federal buildings
1938	Wagner-O'Day Act gave special preference in federal purchasing from workshops employing blind persons
1943	Separate law was established for veterans' rehabilitation
1943	Barden-LaFollette Act expanded the VR program, including emotionally disturbed and mentally retarded, began physical restoration services, and authorized separate blind agencies to administer the VR program
1954	Extensive revisions were made in the Vocational Rehabilitation Act, including financing improvements, establishment of research and demonstration project funding, funding for counselor education, and funding for construction of rehabilitation facilities
1965	After extensive review, comprehensive revisions were made in Vocational Rehabilitation Act, including expansion of services to rehabilitation clients and establishment of National Commission on Architectural Barriers to Rehabilitation of the Handicapped
1965	Amendments to Social Security Act established Title XVIII (Medicare) and Title XIX (Medicaid) programs
1969	National Citizens Conference on Rehabilitation of Disabled and Disadvantaged (NCCRDD) was held
1971	Amendments to Wagner-O'Day Act extended federal purchasing preference to all sheltered workshops for the handicapped and permitted purchase of services as well as products
1973	A comprehensive rewrite of Vocational Rehabilitation Act established priority to serve severely disabled, and mandated an Individualized Written Rehabilitation Program (IWRP) for every client; established Title V protection for certain civil rights of people with disabilities; and changed "Vocational Rehabilitation

Act" to "Rehabilitation Act."

1974 Amendments to the Social Security Act established the Federal Supplemental Security Income (SSI) program and the Title XX (Social Services Block Grant) program

1974 Broader definition of "handicapped individual" was included in the Rehabilitation Act

1975 P.L. 94-142 mandated free appropriate public education for all disabled children

1976 White House Conference on Handicapped Individuals was held

1978 IL program was included in the Rehabilitation Act

1986 Toward Independence—An Assessment of Federal Laws and Programs Affecting Persons with Disabilities—With Legislative Recommendations published by the National Council on the Handicapped

1986 Purpose of the Rehabilitation Act was broadened and rehabilitation engineering and supported employment concepts were incorporated into it

1990 Americans with Disabilities Act established extensive protection of the rights of people with disabilities

1920—Establishment of The National Vocational Rehabilitation Program

The civilian Vocational Rehabilitation program began in 1920 with the passage of the Smith-Fess Act (P.L. 66-236), and since that time has been the traditional provider of services for persons with disabilities with vocational potential. It followed a model instituted in Massachusetts in 1918, and borrowed methodology and techniques from the programs which had already been established to assist World War I veterans.

1943—Inclusion of Persons with Mental Diagnoses, and Establishment of the Rehabilitation Agencies for the Blind

The Barden-LaFollette Act significantly expanded the VR program, by including persons with emotional disturbance and mental retardation, and by including physical restoration in the covered services. It also authorized separate agencies to administer the VR program for persons who were blind.

1954—Expansion Grants Program

Rehabilitation training and research were added to the Vocational Rehabilitation Act and the Innovation and Expansion program had its origin in the Expansion Grants program authorized by the 1954 Amendments.

1965—Comprehensive Planning, and Extended Evaluation of Persons with Severe Disabilities

The 1965 Amendments to the Vocational Rehabilitation Act marked the "opening of the door" to nontraditional clientele. Calling for VR agencies to conduct comprehensive statewide planning, the revised Act reflected a number of changes, including.

- More liberal encouragement of new developments in rehabilitating disabled persons with severe or catastrophic disabilities;
- Extension of the program to reach greater numbers of disabled people;
- Assisting in the construction and operation of new rehabilitation workshops and facilities through liberal federal grants;
- Federal cooperation in the elimination of architectural barriers that stand in the way of rehabilitation of many people with handicaps;
- Expanding training opportunities for persons entering the professions of rehabilitation; and
- Providing for more flexibility in the administration of the vocational rehabilitation program at the level of the states.

Following societal developments of the era, these changes extended services to a broader range of potential clientele. Further, the need to serve individuals with severe handicaps was recognized by provision for extended evaluation, which provided up to 18 months of evaluation of persons applying for vocational rehabilitation services before determination of vocational potential was required. The governing concept behind this provision was that the process of extended evaluation could do much to help the individuals with severe handicaps improve to the point that employment was possible.

1973—Protection of Certain Civil Rights of People with Disabilities

The Rehabilitation Act of 1973 (no longer the Vocational Rehabilitation Act) established several important breakthroughs for persons with severe disabilities. Priority in the delivery of VR services to severely handicapped clients was mandated in the basic program. Section 305 of the Act established the Helen Keller National Center for Deaf-Blind Youths and Adults.

Title V, the "civil rights title for the handicapped," contained important provisions regarding the welfare of handicapped individuals. Sections 501, 502, 503, and 504 of Title V provided for affirmative action programs for the employment of the handicapped within the federal government; for barrier-free work areas in such places;

for the creation of the Architectural and Transportation Barriers Compliance Board; and for nondiscrimination on the basis of handicap for programs and activities receiving or benefiting from federal financial assistance.

It has been said by those who were involved in advocacy for Title V of the Rehabilitation Act that it was not a coincidence that the civil rights section was last. The placement was supposedly purposeful in that, by putting it towards the end, little attention would be given the Title. The Title "Miscellaneous" for Title V was also purposeful. The Rehabilitation Act of 1973 passed with Title V intact, providing the most far-reaching civil rights statutes to date for persons with disabilities.

1978—Establishment of the National IL Program

Passage in 1978 of Title VII of the Rehabilitation Act providing for IL services followed many years of unsuccessful attempts to add this service capacity to the Act.

Though the IL movement and its programmatic efforts were regarded by many as a new phenomenon in rehabilitation, interest in providing these services dated back several decades. In the early 1950s many states had introduced the concept of "mainstreaming" for mentally retarded individuals and had begun providing halfway houses for the mentally ill. During the period from 1959 to 1971, there had been several attempts in Congress to enact legislation for special comprehensive rehabilitation services to improve the IL of persons with disabilities without regard to their ultimate employability. Emphasis in these early bills was on increasing the ability for IL of persons with severe disabilities, thereby reducing their dependence on public programs financed by public taxes.

In 1959, a bill (H.R. 361) had been introduced (and reintroduced later in the year as H.R. 5416) that contained titles relating to IL rehabilitation services. The legislation had proposed an extension of rehabilitation benefits to persons with severe handicaps, even when no vocational objective was obvious.

These bills contained titles relating to IL Rehabilitation Services. The term "independent living rehabilitation services" referred to a variety of services which included but were not limited to counseling, psychological and related services, physical restoration and other related services, needed prosthetic appliances, and training in such skills as would help maintain independent living.

In 1961, bills had been introduced calling for a cooperative arrangement among state agencies administering public assistance, health services, social security and other programs, to provide IL and ancillary services. To assure that attention given to this new program would not detract from the traditional emphasis on vocational rehabilitation, it had been recommended that the two concepts be segregated into separate programs.

The legislation contained a title on independent living rehabilitation services, and included an authorized appropriation amount of $15 million for the first year and $25 million for the second year. The types of services proposed under this legislation

were similar to those previously proposed in 1959, but focused more on mobility, personal adjustment services, and maintenance of rehabilitation gains. There was also a shift from a limited discussion of preventing or reducing institutionalization to improving the life-style of the seriously handicapped individual.

These bills had seemingly been opposed by the administration because the Department of Health, Education and Welfare could not decide who might administer the provisions. Interested units included public health, rehabilitation, and social services (Counts, 1978). In retrospect, this seems to reflect the difficulty in fitting a holistic and consumer-driven program into the existing program structures.

Meanwhile, people with severe disabilities had been initiating a variety of private attempts to solve their own problems. Community-based programs had begun to emerge throughout the country and have continued to do so. They utilized imaginative combinations of funds from sources such as state and federal governments, Innovation and Expansion Grants, Research and Demonstration Grants, and private and local funding.

In 1972, a new bill intended to replace expiring Vocational Rehabilitation legislation had been passed by Congress (H.R. 8395). This bill included comprehensive rehabilitation services and any other goods (including aids and devices) or services provided with funds under titles of the Act that would "make a substantial contribution to helping a handicapped individual to improve his ability to live independently or function normally with his family and community."

The bill included the following definitions:

> A "handicapped individual" means any individual who has a physical or mental disability which constitutes or results in a substantial handicap to employment and can reasonably be expected to benefit from Vocational Rehabilitation services or Comprehensive Rehabilitation services.
>
> "Rehabilitation" means the goal of achieving, through the provision of community rehabilitation services, substantial improvement in the ability to live independently or function normally within the family or community on the part of achieving a vocational goal at the present time.

This legislation had been pocket vetoed by the President who indicated the IL measure would divert the vocational rehabilitation program from its basic vocational objectives, dilute the resources of the vocational program, and impair its potential for continued achievement.

Congress had made some changes in the vetoed bill—none affecting the IL provisions—and in 1973 had resubmitted it to the President, who had again vetoed it. Primarily, the bill had been vetoed because the President's advisors felt the country could not afford a new program that would authorize $30 million the first year and expand to $80 million annually by the third year. Also questioned was whether enough

was known about the needs of persons with severe disabilities and about the ability of the rehabilitation system to meet those needs.

A legislative breakthrough had been accomplished with a compromise between Congress and the Administration which resulted in passage of the Rehabilitation Act of 1973. The provision in the 1972 bill to establish a formula grant program to fund IL services for severely handicapped individuals without a vocational goal had been dropped by Congress. The Administration had agreed to conduct a study of the issues relative to serving the needs of severely handicapped individuals. The Rehabilitation Act of 1973 had then been enacted.

In Section 130, the act had directed the Secretary of Health, Education, and Welfare to conduct a Comprehensive Needs Study (CNS), including research and demonstration projects, to determine various methods of providing rehabilitation and related services to those with the most severe handicaps. Even though the act had failed to provide a formula grant program of ILR, it had established a national policy on services to severely handicapped individuals. In addition, the act had established the IWRP and, in Section 2, given priority of services to severely handicapped clients.

The resulting Comprehensive Needs Study in 1975 had produced a vast body of information. The study had investigated such key questions as: the national population of severely handicapped people, their characteristics, what their needs were, how their needs were being met, and their implications for policy if these needs were to be met more effectively. It revealed that programs serving persons with severe disabilities contained severe gaps in services, suffered from lack of coordination, and were not meeting the overall needs of this clientele. The findings suggested that the specific needs of severely handicapped persons were such that simple expansion of existing VR services in the states was not enough, and that the development of an ILR program was a most crucial need.

Subsequently, on the basis of the authority of Section 130 and the CNS, the Federal Rehabilitation Services Administration had funded five demonstration projects to investigate the following issues:

1. What organizational structure will be most efficient and effective for administering an ILR program?

2. What programs and services are needed for an ILR program, and who should provide them?

3. What manpower will be required and at what level can caseloads be handled?

4. What are the expected outcomes that will result from given levels of expenditures?

5. What would be the relative costs of supporting various ILR goals?

6. What limits should be placed on who is served?

7. Are there persons too severely handicapped to benefit from ILR?

8. What are the objectives of an ILR program for which reasonable accountability can be maintained?

The Demonstration Projects had been selected in such a fashion as to gather as much information as possible. Projects were funded that could address specific delivery issues and specific handicapped populations. Of the five funded, two concerned themselves with medically-oriented physical restoration services, two with the role of State agencies in ILR, and one with a consumer-based-and-operated ILR program. The Urban Institute report (Counts, 1978) on these projects offered the following judgment:

> The results of these projects clearly indicate that additional investments in IL rehabilitation activities for severely handicapped individuals are warranted. Other programs should be established having different administrative structures and service components. Persons with a broader cross-section of disabilities should also be involved in subsequent IL innovations. (p. 63)

In 1974, the Rehabilitation Act of 1973 had been amended to include a broader definition of the term handicapped individual. This was done in part to augment the implementation of Title V. However, it focused on major life activities rather than vocational objectives. It also authorized the White House Conference on Handicapped Individuals, which for the first time provided a national forum for people with handicaps to express their views and make recommendations for public policy to address their concerns.

Finally, conditions were right and the 1978 Amendments added Title VII, Comprehensive Services for IL, to the Act. The issues that had frustrated previous attempts were this time negotiated and worked through. The title provided support for involvement of both the state rehabilitation agencies and the developing ILCs. Part A of the title, patterned after the Title I VR program, authorized state-agency administered programs of "comprehensive services for independent living"—essentially that which is defined in this document as ILR services. Part B of the title, developed mostly as new statutory language, authorized support for the establishment and maintenance of ILCs. Parts A and B were interlinked through some state plan requirements specified under Part A, and through a requirement that 20% of the funds received by a state under Part A were to be used to make grants to local public agencies and private nonprofit organizations for the conduct of IL services.

Some issues involved in passage of Title VII are still being negotiated and worked through. None of the parts have been funded at levels expected by those who fought for passage. Many saw Part A primarily as a means for providing ongoing funding for ILCs and not as an ILR services program administered by the state rehabilitation agencies. Many similarly saw Part B as merely "start-up" or "seed" money and not as a source of ongoing core funding for ILCs. From a statutory perspective, state agencies were given specific authority for IL services, supplemental to their VR role. In this connection, they were also given a mandate to actively listen to consumers. However, although asked to take on a new population and service responsibility, they

were not given the funding needed to do so. The debate, and the evaluation of the rehabilitation system, continue—currently reinvigorated by examinations and proposals related to pending reauthorization of the Rehabilitation Act.

1984—Evaluation of IL Services

In 1984 Congress made some technical changes to the Rehabilitation Act. One of the additions was a requirement to conduct a comprehensive evaluation of the Centers for Independent Living Program. The evaluation section of the act mandated the development of and approval by the National Council on the Handicapped a set of standards for evaluation. These standards were to reflect the 11 specific areas of interest to Congress. The process for developing the evaluation standards ensured broad input from ILCs, consumer advocacy organizations, researchers, and policymakers. The evaluation standards then were approved by the National Council on the Handicapped for use in the evaluation. In addition to their role in the national evaluation, the standards were also designed to serve as a self-evaluation tool for the centers.

The study (Berkeley Planning Associates, 1986) was commissioned by the U.S. Department of Education and conducted by Berkeley Planning Associates in conjunction with The Center for Resource Management and The Research and Training Center for Independent Living at the University of Kansas. Study findings primarily reflected data from the 1984-1985 project year, during which the 156 centers received Part B funds totaling $21 million, at an average award of $134,000. The average Part B funding for the 121 responding centers was $133,000 with a median of $130,000. State rehabilitation agencies acted as the Part B grantee for 79% of the 121 centers responding to the survey, generally subcontracting to local community organizations to provide services (69%). A few rehabilitation agencies operated ILCs themselves (10%). The remaining 25 centers received funds directly from the federal government (21%).

The results of the evaluation were reported by the ten (A-J) evaluation areas specified in Part B legislation (Section 711(c)(3)). Highlights of these results are included in Appendix C.

Evaluation of the various IL efforts continues, and many unanswered questions remain. However, it is obvious that the need for these programs exists, and IL services should not be viewed as a futuristic concept but rather as an idea whose time has come. As can be seen by the results of the evaluation, the outcomes of the meager resources provided for the ILCs are significant. It is clear that additional resources are needed to more adequately address the needs of the many hundreds of thousands of persons with disabilities and to empower those individuals towards greater independence.

1986—A Broadened National Purpose

In 1986 the Rehabilitation Act was amended to recognize in more detail the broadened purpose of the national system. Correspondingly, the statement of purpose was revised to include more detail about independent living, as follows:

The purpose of this Act [29 USCS ss701 et seq.] is to develop and

> implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living, for individuals with handicaps in order to maximize their employability, independence, and integration into workplace and the community. (Section 2)

The Amendments also more precisely defined persons with severe handicaps. The Congress took this action so that vocational rehabilitation agencies might have more uniformity in identifying and reporting services to persons with severe handicaps.

There were also many other substantive changes to the Rehabilitation Act. Perhaps, however, the most important outcome of the significant changes was a shift in the way Congress saw persons with disabilities. In concept, the rehabilitation system was now clearly not to deal only with the work environment, but with the other 16 hours a day as well. In just a few short years, this broadened purpose reflected in the Rehabilitation Act helped set the tone for passage of the Americans With Disabilities Act.

This shift had been foretold when, on March 22, 1988, Congress overrode President Reagan's veto of a civil rights restoration act. The primary intended effect of this act was to overturn the Grove City decision by the Supreme Court. This decision had severely limited the coverage of various civil rights statutes by applying them only to those who directly received federal funds. The effect of the restoration act was to return coverage to its original interpretation—that is, if any part of the program or activity receives federal funds, then all aspects of the program or activity are covered.

The changing times for people with disabilities in the United States were then brought to a new focus by a well-attended ceremony in Washington. With many of the leading advocates for the rights of people with disabilities looking on (many of them also consumers in their own rights), President Bush signed the Americans with Disabilities Act on July 26, 1990. The century-long evolution of American policy concerning people with disabilities had reached a major milestone, and a new agenda was being set as the country moved toward the next century. A trend was set, the direction of history was clear, and the changed direction is not likely to be reversed.

Current Legislative and Statutory Bases of the National Rehabilitation System

The national rehabilitation system, including both VR and IL programs, operates directly under the authority of the Rehabilitation Act and is strongly impacted by several other federal laws. These are briefly identified and outlined below.

The Rehabilitation Act of 1973, as Amended

The Rehabilitation Act as amended, has seven titles and addresses many aspects of the lives of persons with disabilities. A brief description of the titles follows:

Title I—Vocational Rehabilitation Services

This title addresses the various aspects of providing funding for vocational rehabilitation services. It is divided into four parts which address the various aspects of the provision of VR services. In addition to setting out state plan requirements and the formula and process for the distribution of funding, the title also specifies the rights of the consumer including the right to an IWRP; the right to annual review of the IWRP; the right to joint redevelopment and agreement of terms; and the determination of whether the vocational goal is being achieved.

The title also sets out the scope of vocational services, individual services, and services to groups of individuals. It further sets out the requirement for a Client Assistance Program which assists individuals who receive services under the Act to get advocacy assistance.

Finally, Title I provides for the issuance of Innovation and Expansion Grants when funds are made available by Congress, and for the provision of Vocational Rehabilitation services to American Indians.

Title II—Research and Training

This title addresses the priority Congress places on the need for research and training concerning the provision of services to persons with disabilities. The title establishes and names the National Institute on Disability and Rehabilitation Research (previously the National Institute on Handicapped Research). The title also establishes research grants to qualified public or private agencies and individuals, and requires a long-range plan for rehabilitation research to be reviewed by Congress. In addition, it sets out the requirement to cooperate and coordinate research between the various agencies of the federal government.

The title sets out grants for training to the various qualified organizations; a report to Congress on training needs; study of health insurance practices and a report to Congress regarding this issue.

The title also sets out the authorization for certain research and demonstration projects including: multiple and interrelated service needs of handicapped individuals with a report to Congress; and a study of the impact of Vocational Rehabilitation services with a report to Congress.

Title III—Special Federal Responsibilities

This title sets out the authorization of grants for the construction of rehabilitation facilities and the provision of funds for staffing and planning assistance of same.

A section is included to address the need for vocational training services for persons with handicaps. There are also sections to: provide loan guarantees to

rehabilitation facilities; provide training grants and contracts for personnel projects relating to training, traineeships and related activities, training related to interpreters for the deaf, the evaluation of the various programs under the section, and the provision of technical assistance to state rehabilitation agencies and rehabilitation facilities; and, develop comprehensive rehabilitation centers.

There is also a separate area in Title III entitled "Special Projects and Supplementary Services" which establishes special demonstration programs and grants to state and public and nonprofit agencies and organizations. The special projects address many areas: individuals with spinal cord injuries, job training for youth with handicaps—preparing them for entry into employment, supported employment programs and the requirement to provide a report to Congress regarding same, transitional planning services for youth with severe handicaps and the collection and dissemination of data.

There are also sections regarding migratory workers, reader services to blind persons, interpreter services to persons who are deaf, and special recreation programs.

Title IV—National Council on Disability

This title establishes and names the National Council on Disability (previously the National Council on the Handicapped). It sets out the duties of the National Council; establishes its staffing, and sets out its responsibilities. Although this is one of the shortest titles in the Act, the Council has significant responsibilities including holding public hearings on important issues relating to disability and making reports to Congress regarding such issues of importance.

Title V—Miscellaneous Provisions

Although Title V is entitled "Miscellaneous Provisions," it is the civil rights title--one of the most far-reaching of all titles in the original Rehabilitation Act of 1973. The various sections address a broad range of issues regarding the lives of persons with disabilities.

Section 501 deals with the issue of employment in the federal government and establishes a Federal Coordinating Committee regarding employment of persons with handicaps.

Section 502 establishes the Architectural and Transportation Barriers Compliance Board. It sets out the various responsibilities of the Board and the procedures for dealing with the Board's responsibility of determining whether or not the various agencies who receive federal funds are in compliance with the Federal Barriers Act. The section also mandates reports to Congress regarding transportation and housing needs of persons with handicaps. Finally, the section mandates the Board to report to Congress on how states are expending funds to address full access to programs and activities for persons with handicaps.

Section 503 addresses the requirement of equal employment opportunity under federal contracts and sets out the administrative enforcement, complaints and investigations procedures for compliance under this section.

Section 504 provides for nondiscrimination for persons with disabilities by any recipient of federal funds and sets out the requirement for promulgation of rules and regulations. In addition, the section defines program or activity and provides for remedies and attorneys' fees.

Various other sections under Title V establish the requirement for an Interagency Coordinating Committee and for annual reports to Congress, and the need to address electronic equipment accessibility by establishing guidelines that were to be promulgated by 1988.

Title VI—Employment Opportunities for Individuals with Handicaps

Title VI establishes the newest program area in the Act, entitled "Community Service Employment Programs for Individuals with Handicaps." This section establishes pilot programs for employment for persons with handicaps and determines the various administrative aspects of this new section. In addition, it sets out the administration of the program through the state VR agencies and requires the coordination with other programs.

Another area of the title is entitled "Projects with Industry and Business Opportunities for Individuals with Handicaps." This section establishes the Projects with Industry Program (PWI) and sets out the various administrative and review requirements. In addition, the section establishes the need for indicators for compliance with evaluation standards, the requirement of compliance reviews, the need to provide technical assistance to entities conducting or planning Projects with Industry, and priority to unserved or underserved areas. This section also establishes business opportunities for persons with disabilities.

The final area of Title VI, Supported Employment Services for Individuals with Severe Handicaps, establishes allotments to the various states to fund supported employment projects. In addition, the section sets out the requirement for the development of a state plan and puts in statute the principle that supported employment is complementary to vocational rehabilitation services.

This newest section of the Act recognizes the need to provide support for persons with severe disabilities in order for them to work in competitive jobs in the community. This new philosophy is in tune with the IL philosophy that persons with disabilities should be living and employed in the most integrated setting possible.

Title VII—Comprehensive Services for Independent Living

Part A of this title, Comprehensive Services, sets out Congressional statement of

purpose and eligibility for IL services, authorizes grants to assist states in carrying out this purpose, and defines state agency responsibilities. State allotments for Part A, the requirement for state share, and state plan requirements are set out. Establishment by the state agencies of the State Independent Living Council is also specified, including descriptions of its responsibilities, membership composition and chairperson duties.

Part B, or Centers for IL, is the next area defined in Title VII. The establishment of centers by grants, the process of application for funds by eligible public or nonprofit agencies or organizations, the priority to state agencies for first opportunity to apply for funding, and the requirement for boards composed of a majority of persons with disabilities to oversee operation of ILCs are set out. In addition, this section sets out the requirement for standards for evaluation, approval of standards by National Council on Disability, a national evaluation of centers, indicators for compliance with evaluation standards, and the need for annual on-site reviews.

Lastly Part B sets out priority for unserved geographic areas for new grants and the requirement for competition for funds during the last year of reauthorization.

Part C establishes a program of Independent Living Services for Older Blind Individuals. This section authorizes grants for state agencies to provide IL services and provides for grants to public or private nonprofit agencies by said agency to carry out the purposes of this part.

Part D, or Protection and Advocacy, establishes the development of Protection and Advocacy programs for persons with disabilities.

Other Laws appended to Title VII include the Helen Keller National Center Act which defines and authorizes operation of the Helen Keller National Center for Deaf-Blind Youths and Adults.

Other Legislation Affecting the Disability Movement

Some of the other major laws that have or will have positive implications for persons with severe disabilities are as follows:

- Education For All Handicapped Children Act of 1975 (P.L. 94-142) which called for a sharply increased federal commitment to insure that all handicapped children receive full and appropriate educational services.

- Carl D. Perkins Vocational Education Act of 1984 (P.L. 98-524) and its predecessors offered vocational education to handicapped students, primarily at the secondary level.

- Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103) which provided funds to assist states to provide services cutting across traditional program boundaries and protection-and-advocacy assistance for persons with severe disabilities occurring prior to age 22.

- Title II of the Social Security Act of 1935 (Chapt. 531, 49 Stat. 620) (Social Security Disability Insurance, [SSDI]) which provided monthly disability insurance payments to workers with disabilities and their eligible dependents.

- Title XVI of the Social Security Act, including P.L. 94-566, P.L. 94-569, and P.L. 94-585) (Supplemental Security Income, [SSI]) which established SSI benefits to aged, blind, and disabled individuals and created a new assistance program for SSI-eligible children.

- Titles XVIII and XIX of the Social Security Act (Medicare and Medicaid) which provided hospital and medical insurance protection to disabled workers as well as funding for state medical assistance programs for the poor, including persons with disabilities.

- Title XX of the Social Security Act (Social Services Block Grant) which provided funds for an array of social services. Originally conceived as a key program for the comprehensive planning and funding of state social services, the act was revised and scaled back in 1981 to its current "Social Services Block Grant" form.

- Housing Act of 1959 (P.L. 86-372) which provided loans for construction or rehabilitation of housing for the elderly and people with handicaps (Section 202) and a voucher rent subsidy program (Section 8).

- National Housing Act Amendments of 1975 (P.L. 94-173) Title I which included provisions for the removal of barriers, hazards and inconvenient features of housing for people with handicaps, to be implemented by the newly established Office of Independent Living for the Disabled within the Department of Housing and Urban Development (HUD).

- Architectural Barriers Act of 1968 (P.L. 90-480 as amended by P.L. 94-541) which addressed barrier-free design in Federal buildings and facilities.

- Federal-Aid Highway Act of 1973 (P.L. 93-87) as amended by P.L. 93-643 which required access to public mass transportation facilities, equipment and services for elderly and persons with disabilities.

- Department of Transportation Appropriations Act of 1975 (P.L. 93-391) which directed that none of the funds under the act be available for purchase of mass transit equipment or construction of facilities unless they meet the requirements of the elderly and handicapped.

- Air Carriers Access Act of 1986 (P.L. 86-372) which prohibited discrimination against any "otherwise qualified handicapped individual" in the provision of air transportation. (Regulations for this act were recently promulgated.)

- Fair Housing Act Amendments of 1988 (P.L. 100-430) which added persons with disabilities to the civil rights protections for racial minorities and persons who are discriminated against on the basis of religion, sex, or national origin.

- Technology Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 101-476) which provided assistance to states in creating consumer-responsive, statewide programs of technology-related assistance for individuals of all ages and disabilities.

- Americans with Disabilities Act of 1990 (P.L. 101-336) which provided "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities," including titles on employment, public services (general, and transportation), public accommodations and services operated by private entities, telecommunications, and miscellaneous provisions.

The concept of rehabilitation services has changed over the years. Medical and rehabilitation technologies have made such advances in the past two decades that many of those who would have been targets for IL services in the 1960s are now rehabilitated by the VR programs. Advances in prosthetics, orthotics, communication and other technologies, medical science, and in the provision of services, have vastly expanded the number of persons who can be vocationally rehabilitated, and increased the range of life options available to people with severe disabilities.

Yet, the national rehabilitation system, as reflected in the above summary of legislation, goes far beyond VR and IL services and, indeed, far beyond the statutory limits of the Rehabilitation Act. The Americans with Disabilities Act (P.L. 101-336, Section 2[a][7] & [8]) provides a powerful statement of the situation:

> ...individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.
>
> ...the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals...

Viewed in its entirety, the rehabilitation system is the nation's array of disability and related services which are committed to working in collaboration to achieve these goals.

The IL Philosophy as a Movement and a Service Delivery System

In order to address the appropriate roles and responsibilities of ILCs and other IL service providers in delivering VR services, it is necessary to understand their environment, mission, and nature. This part of the chapter examines these aspects of IL, including the roots of the IL movement, IL as a philosophy, and the development of the IL philosophy as a service model.

Roots of the IL Movement

The evolution of the broad civil rights movement for persons with disabilities into the practical philosophy of the IL movement has many different roots. In the middle 1950s, some rehabilitation professionals including E. B. Whitten, the Executive Director of the National Rehabilitation Association, proposed a comprehensive services system as an alternative to the vocational system. E. B. Whitten and others felt that those whose disabilities were "too severe for vocational potential" should have an alternative to living in an institution or depending completely on the family.

This alternative to the VR model did not materialize as proposed by the rehabilitation community. There are many reasons why this alternative system was not realized. Certainly cost was a major factor, but just as importantly persons with disabilities were not speaking on behalf of themselves and their needs. It would take nearly two decades before people with disabilities would realize that denial of equal access to a building or alternative living situations for mentally retarded adults was as much a civil rights issue as denial of equality for women. It would take people with disabilities nearly twenty years before they realized that they must speak for themselves, and before change would finally begin to take place. They would finally realize that it was as much a civil rights issue for them to be denied access to the bus as requiring blacks to ride in the back of the bus or not providing a quality education for all people.

The National Rehabilitation Association, through its Journal of Rehabilitation, issued a "Report of Ten Years of Rehabilitation Progress under P.L. 565." Several leaders in the rehabilitation movement were invited to write about their views. E. B. Whitten (1964) speculated that the future of vocational rehabilitation would involve fundamental changes in social attitudes towards disability, reaching into each community with the pervasiveness of public education. This would, he suggested, require more extensive participation on the part of the community in the rehabilitation of citizens with disabilities. He saw greater concern and involvement of organized labor, the medical professions, colleges and universities, and employers in the problems of disability. Rehabilitation, he suggested, like health and education, was likely to be increasingly regarded as a right rather than a privilege.

During the 1960s, a few people began to speak out about the inhumane treatment and the lack of control persons with severe disabilities had over their own lives. This began happening on a very spotty basis throughout the country. In "Independent Living: The Concept, Model, and Methodology," James Budde and Judy Bachelder (1986, p. 241) report one of the earliest developments: "In 1962, four students with severe disabilities were transferred from an isolated nursing home to an accessible residence closer to their campus at the University of Illinois at Champaign-Urbana. They helped make the university accessible and formed some of the initial IL self-help policies."

Ed Roberts and Judy Heumann in Berkeley, California, are considered by many to be the two persons who have had the most influence in the development of the IL philosophy. Ed Roberts and several other persons with severe disabilities are credited

with originating the ILC concept while attending the University of California at Berkeley. They were initially housed in Cowell Hospital on the campus. Forming a group called the "Rolling Quads," they began discussing ways to break the segregated, caretaker quality of life on campus. Their efforts helped define some of the key philosophical concepts of the IL movement. Among these were the notions that they could get out of the hospital and live like everyone else; that they were "consumers," not "patients;" and, that they could eliminate segregation from their lives. They formed a program office, and within a year, off-campus consumers were a sizable proportion of those seeking services. This interest from consumers prompted Roberts and his associates to establish an ILC for the community-at-large. This was the beginning of the ILC model, incorporating consumer-control, self-help, and community advocacy as fundamental principles.

Roberts and Heumann felt that people with the most severe disabilities should have the right to decide where they lived, ate, worked or traveled—in essence, that people with the most severe disabilities should have the same options as others. Remember, most persons with severe disabilities were in that era relegated to living in institutions, so that belief in the right of an individual with a disability to the same options as others was a revolutionary philosophy.

It is certain that the civil rights movement begun by Dr. Martin Luther King and others for black people had a profound effect on the consciousness of others in this country. Women began to speak out for their civil rights. Other minorities and interests also began to advocate for change to positively affect their own constituencies. This included initiatives as diverse as those of; consumerism; the self-help movements; the drive for demedicalization of care and a commensurate emphasis upon self-care; and the move toward deinstitutionalization, normalization, and mainstreaming. The IL movement must have been influenced by this new awareness that people should not be judged solely because of their skin color, their sex, or any other factor that might appear to make them "different." Also contributing were the related principles of self-determination (consumer sovereignty), self-help (self-reliance), and mainstreaming (political and economic rights).

At the same time, disabled veterans who were returning from the Vietnam War were finding themselves excluded from participation in the community simply because of their disabilities. The survival rate of those injured in the War approached 95% of those making it back to the field hospital. The helicopter had become the aircraft of the Vietnam War, especially for transporting troops and for field evacuation of those injured. Thus, getting to the field hospital was extremely efficient and life saving.

This large number of persons who had previously lived in their communities without disabilities, now came home with severe physical disabilities and found that their communities were not accessible. They soon formed and became a political force through the Paralyzed Veterans of America (PVA) and the Disabled American Veterans (DAV). These two groups were a major force behind the passage in 1968 of the Architectural Barriers Act. This act required that all new buildings built in part or whole with federal funds must be physically accessible. The law had no teeth, but it was the beginning of a political statement for persons with disabilities.

A visible force of persons with disabilities began to gather momentum in the early 70s. At the same time that Ed Roberts and Judy Heumann were working on the first center for independent living in Berkeley, California, other persons with disabilities were beginning to meet in small groups across the country. There was no national organization or any particular structure for the groups. In many places, they were simply social clubs. In other locations, they took on a more activist role, with formalized ILCs starting in places such as Boston and Houston.

Passage of the 1973 Rehabilitation Act was testimony to this new political entity. However, it was not until 1976 that the first national organization, The American Coalition of Citizens with Disabilities (ACCD) was formed in Washington, D.C. ACCD was the first cross-disability, grass roots organization of persons with disabilities. Local coalitions were formed in various places throughout the country including California, New York, Pennsylvania, Virginia, Maine, and Oklahoma.

Even then, except for the organizations mentioned above, there were only a few hundred people involved in this new IL movement. For the most part, this original consumer network was an informal group of people who usually met in their own homes or available common meeting places. Many of these were people with disabilities who were succeeding *in spite of* the rehabilitation system, after having been classified by the system as too severely disabled for services. Their cause was also joined by some committed people who did not have disabilities, including staff from agencies and organizations serving people with disabilities, and other supporters. Gradually, these pioneers began to establish pilot IL projects and programs, and to influence others to join the growing movement.

The IL movement thus began to take its place at the forefront of the historic and long-term disability rights movement, and a new force to establish and assert the civil rights of people with disabilities was born. An excellent expression of the scope and focus of the IL movement, as well as its relationship to the disability rights movement, is provided by the "Disabled People's Bill of Rights and Declaration of Independence" found in Appendix D. This statement, attributed originally to the ILC at Berkeley, California, has circulated widely and been adapted for use by many ILCs/ILPs. After endless years of oppression, people with disabilities began to recognize that they should not be treated differently simply because they happen to have a disability!

Independent Living as a Philosophy

The progress society has made in developing a social philosophy to address the oppression of many of its minorities has only recently included those persons who have disabilities. Until the early 1970s, it was believed that the lives of people with disabilities should be controlled by others in order to "protect" them from experiencing failure. It was "the system" that knew better, that determined who would succeed and what vocational goals would be set for the person. The system and its approach perpetuated the philosophy that the individual with the disability was the *problem*.

With the IL movement, a few individuals across the country began to promote a philosophy holding that all persons should have the right to self-determination. The right to choose one's own destiny was as important for persons with disabilities as it

was for any other minority. The individual was the *solution,* not the problem. Failure was a way of learning that was experienced by all, and so should be an option for people with disabilities as well. This change in perception of where the problem lay was for many people a foreign concept that was not easily accepted. Gaining support for this philosophy would take work.

This new feeling about the right of an individual to self-direct to the fullest extent possible became known as the IL philosophy. IL became the backbone of the civil rights movement for people with disabilities. It recognized that access to the community, jobs, transportation, housing, and all the other things that most people took for granted, was (and should be) the right of a person who had a disability. This philosophy set the foundation for a movement to convince people that individuals with disabilities were the solution, not the problem, and that they should be empowered to act for themselves.

The common thread throughout the movement was the issue of who was making the decisions, and who was developing the issues. People with disabilities were, for the first time in history, actively involved in determining their own destinies. The cornerstone of the IL movement had been laid! Unlike the early unsuccessful attempts by people from the rehabilitation field to fund community-based services, this time those who would benefit from those services were in control.

The concept of consumer control and self-determination was certainly not a new concept. It had been articulated in history when the French Revolution occurred. It had been a factor when much of the Roman Empire crumbled under the weight of the need for political identity. It had been demonstrated in the 1950s when Dr. King and others from the civil rights movement spoke out about the injustice of discrimination against black persons. And, now, it was happening for and by persons with disabilities. They were saying that being excluded from participation in the community because of a disability was wrong. Discrimination was occurring against people with disabilities because there were no community services, because there was no access to education, and because there was no accessible housing or transportation.

A very important aspect of the emerging IL philosophy was the idea of risk-taking and the right to fail. The right to fail, and therefore the right to take risks, derived from consideration of who was most qualified to make decisions for people with disabilities. The traditional rehabilitation system had, for years, mandated that the chance of failure be minimized for its clients. The root of this programmatic mandate was simple; the problem was with the individual, thus, he/she must be changed or fixed. The IL philosophy reversed that approach by holding that the individual with the disability was the locus of the solution and not the problem.

Once the individual is recognized as the locus of control, then it follows that the individual must have the right to take risks. Trying career fields that have not been traditionally viewed as acceptable for those with disabilities becomes necessary, because risk-taking is the historical basis for the development of careers. It would have been unthinkable for Franklin Roosevelt not to run for president because of his disability. Yet, it was only because of his political power that he was able to take this risky step into history. With the development of the IL philosophy, each person with a disability

was empowered to take such risks.

The philosophy of IL was born. It affirmed a wide array of rights for people with disabilities, including (among others) the right to self-direction, the right to community access, the right to live in an accessible community, equal treatment under the law, use of accessible transportation, and the availability of affordable and accessible housing. The IL cornerstone of consumer control and self-determination, buttressed with an emphasis upon self-help and peer support as well as political and social activism, laid the foundation for a movement that would fundamentally alter the rights of people with disabilities.

The Development of the IL Philosophy as a Service Model

The earliest days of the IL movement were based on the concept that, with the need to look at access as a civil rights issue, there must also be the understanding that community-based services were equally important. This coupling of equality of access (both programmatically and physically) with the necessary services to assist one to live in the community was a practical aspect of disability. IL does not necessarily mean that people must or should live independently, but rather that they must have control over their lives.

Thus, a community-based, consumer controlled resource center needed to be available to assist the individual to access the necessary services, to act as a political force for community change and, when necessary, provide certain services that were not available anywhere else.

In the very early days of the ILC movement, the primary services in addition to advocacy were assistance in finding a personal care attendant (PCA) (now more appropriately called personal assistant or personal assistance services [PAS]), housing referral, and transportation assistance. As more resources became available through Title VII of the Rehabilitation Act as amended in 1978, a more organized definition developed of what services constituted an ILC. Additional core services began to evolve through a conscientious and thorough national review of the basic services described in the original Title VII legislation and amendments. The core services that evolved were: advocacy (individual and systems); information and referral; peer counseling; and IL skills training. The National Council of Independent Living, organized in 1983, became a major force in developing these core services and other major policy issues surrounding IL services.

The core services became the reference for new funding when, in 1986, the National Council on the Handicapped adopted its Standards for ILCs (Berkeley Planning Associates, 1986). These standards, which were required to be developed and approved by NCH in the 1986 Amendments to Title VII, also set out formally the need for consumer control in both the staff and boards of ILCs.

The following questions and answers (Kailes, 1990) perhaps best describe the ILC model today.

What are ILCs?

ILCs are consumer-controlled, community-based organizations that help people with disabilities achieve or maintain more self-sufficient and productive lives in their families and communities. They do this by developing community options and by empowering people through the provision of information, peer support, advocacy, and skills training. Communities are encouraged to make changes and develop resources so that increased options are available to people with disabilities. People with disabilities are assisted in exploring alternatives to dependency and are encouraged to make their own decisions about how and where they live.

Consumer services which the ILCs directly provide or coordinate through referral assist people in increasing their abilities to exercise control over their lives. Control over one's life means having a choice of acceptable options that minimize reliance on others in making decisions and performing everyday activities. This includes managing or directing one's own affairs, participating in day-to-day community life, and fulfilling a range of social roles.

How are ILCs Unique?

Most fundamentally, the ILCs are unique in that they are part of the IL movement and their mission is that of the movement. This leads to several features that set ILCs apart from other organizations and agencies. These unique features are presented.

Consumer Control. Within the IL movement, there is a strong belief that peer conducted services are essential to assisting a person with a disability. Therefore, 51% or more of the ILCs' Boards of Directors and substantial numbers of the staffs are people with disabilities who have personally experienced attitudinal, physical and communication barriers. Their experiences have resulted in unique commitments to assist others with disabilities achieve lives of dignity. Staff serve as role models, demonstrating that it is possible and desirable for people with disabilities to be productive and independent. The understanding, guidance and support provided through ILCs give others the confidence to take the first steps toward their own independence.

The service philosophy is also based on consumer control. Emphasis is placed on consumer self-direction and control to the greatest extent possible, in contrast to service models in which the client/patient is highly dependent on experts. The move from dependence on staff to self-direction marks a shift from the client/patient mentality to a consumer mentality. The client/patient mentality involves accepting without question the wisdom of the experts—trusting and obeying. In contrast, the consumer mentality involves individual goal setting and personal choices regarding health care, life style, vocation, education, and advocacy.

Community Development. Following the IL philosophy, the ILCs provide

community development as well as direct services for individuals with disabilities. ILCs advocate for the improvement of the quality of life for all people with disabilities, and seek to eliminate society's attitudinal, environmental, social, psychological and economic barriers to equal opportunities.

Holistic, Cross-disability Focus. Unlike many agencies which only serve people with specific disabilities or service needs, ILCs offer a broad range of community-based services for people with a variety of disabilities in all age groups. Services are available throughout the lifetime of a person with a disability. ILCs are also unique in that they do not restrict or limit services to vocational, job-related, or other limited areas of need. They respond in a holistic manner to whatever problems and needs the person with a disability has brought to them for discussion and assistance.

View of Disability. ILCs are further unique in the view of disability they promote. While society in general still views disability as something to be ashamed of, the ILCs promote positive self-concepts, disability identification, and disability pride. Disability is related to problems with the environment rather than to physical impairment. It is the environment which frequently causes the real disability—such as not being able to negotiate steps into a building, not being able to hear a speaker, or not being able to read printed material. ILCs promote an environment designed for everyone.

What Impact Have the ILCs Had?

The efficacy of the IL movement and its concepts are being proven daily by more and more people with severe disabilities as they choose to assume the responsibilities of directing their own lives and to become active, contributing participants in the mainstream of life in the communities. As the movement has gained momentum, the public is becoming more aware of the abilities of people with disabilities and more supportive of the services needed to maximize those abilities.

ILCs have kept thousands of people out of institutions and have also changed the status of many people with disabilities from unemployed to employed, and from institutionalized to functioning independently in the community as productive citizens. Escalating numbers of people with disabilities are contacting ILCs to request advocacy and services, and also to join in the demand that the status quo no longer be accepted. The push for equality, integration, and civil rights is gaining momentum and growing in force.

IV. IMPLICATIONS:

The disability rights movement has traveled far, from an early belief that disability was a deserved consequence of injustice or sin, to the current drive for self-determination, independence, and community integration. The national rehabilitation system began with a narrow focus upon employment, but has gradually broadened to include a wide range of rights and services for people with disabilities. Within this context, the IL movement developed as part of the civil rights movement out of a

concern for people with disabilities. The philosophy upon which it is based holds that people with disabilities have the right to control their own lives and have access to the same options as others.

The movement seeks to empower people with disabilities to participate fully in the affairs and benefits of society through provision of a broad range of information, advocacy, community development, and skills training services. It helped bring about passage of Title VII of the Rehabilitation Act, which established the framework for IL services and their holistic, empowerment emphases to become integral parts of the nation's rehabilitation system. The current challenge is to identify the specific roles that ILR services and ILCs/ILPs can appropriately play in the national rehabilitation system, and to find ways of making them full partners in that system. The results will include increased consumer success in obtaining and (most importantly) maintaining employment, and in taking control and responsibility for their own lives.

Note should be taken of two prevailing concepts which must be addressed in constructing this partnership—that IL services are only for those with *severe* disabilities, and that duplication of services must be avoided. Although both of these concepts have current statutory basis, the evolution of IL services and the demands of an IL/VR program partnership both require that the application of these concepts be reconsidered.

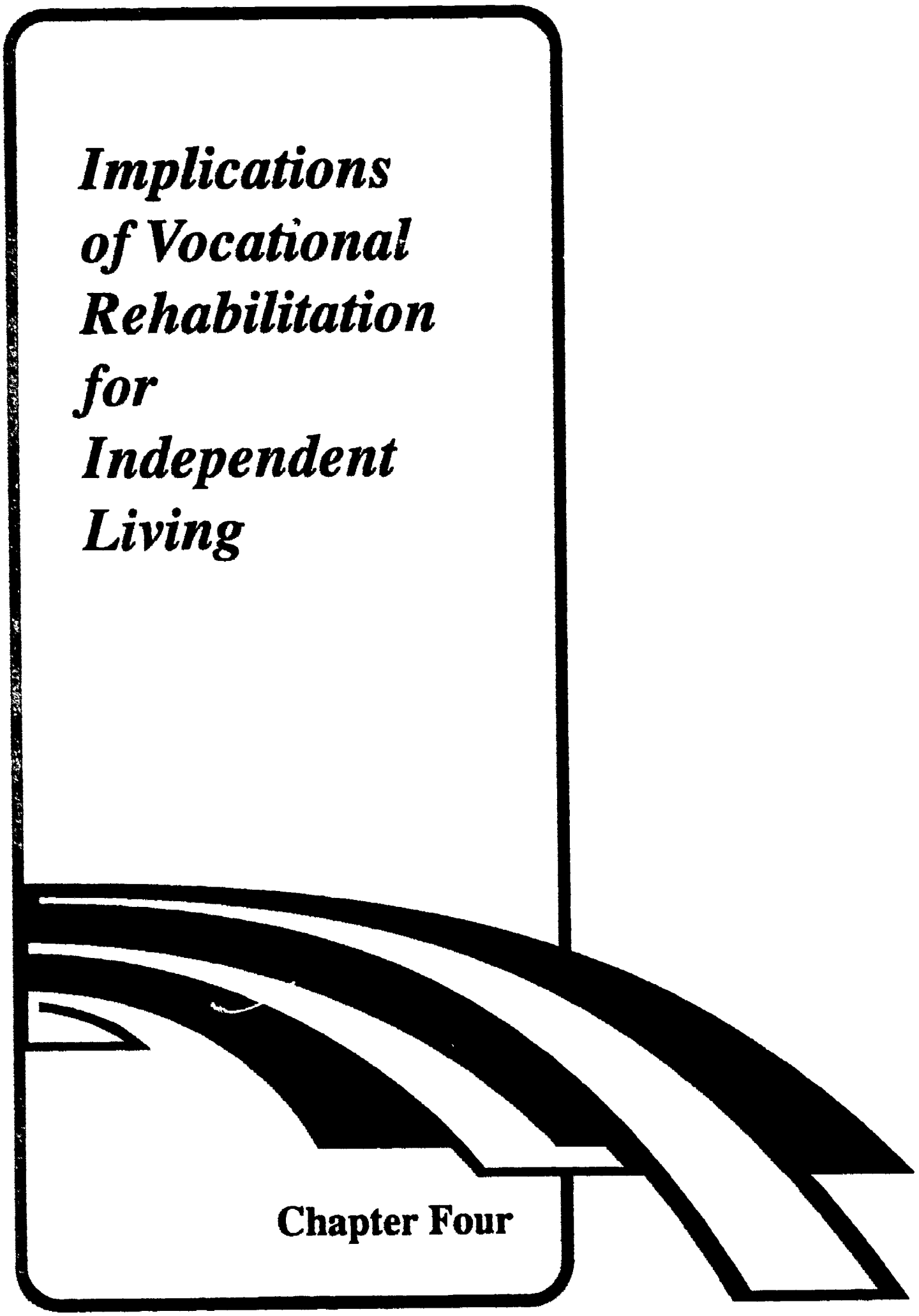
As currently written, the opening purpose of Title VII of the Rehabilitation Act relates to "individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently" (Section 701). Although this purpose is technically included in Part A of the Act, it stands as the opening statement of purpose for the whole act because there is no other preamble or introductory section. This very restrictive focus on persons with severe disabilities is, however, almost immediately broadened in the description of eligibility for ILR services under Part A of the Act. The next section still specifies the need for "services appreciably more costly and of appreciably greater duration than those vocational or comprehensive rehabilitation services required for the rehabilitation of an individual with handicaps" (Section 702(a)). However, it includes services "to improve significantly either the ability to engage in employment or the ability to function independently in the family or community" (Section 702(a)). It also addresses the nonduplication of services, stipulating that service priority is to "be given to individuals not served by other provisions of this Act" (Section 702(a)).

The matter is further confused in the Part B section on ILCs. This section does not define any specific target or eligible population, but merely notes that the centers "shall offer individuals with handicaps a combination of independent living services" (Section 711(c)(2)).

The historical and legislative perspectives discussed in this chapter suggest that reauthorization of the Rehabilitation Act should be accompanied by reconsideration of the relationship of VR (Title I), ILR (Title VII, Part A), and ILC (Title VII, Part B) services, as well as other parts of the act. The statutory language should be clarified to require and support a constructive partnership, especially between VR and IL services.

Twelve years of experience with Title VII has demonstrated that restrictive application of the c ncepts of severe disability and nonduplication of service is often inconsistent with constructive partnership. An overall purpose of Title VII needs to be stated in ways that encompass the full range of ILR, ILCs/ILPs, and other included services—and more fully reflect the IL movement and its place within the broader disability rights movement. Moreover, the parts dealing with ILR and ILC services (Parts A and B) need to specify purposes that accurately reflect the appropriate roles of those services within the national rehabilitation system, as well as the appropriate roles of other programs and services established by the act. This includes recognition that ILCs are properly established to serve *all* people with disabilities (not only those with severe disabilities), that IL services are often appropriately provided *in conjunction* with VR services, and that ILC's/ILP's services that seem similar to those of other organizations or agencies may, in fact, not be duplicative because they are providing service access or combinations of services that would *not otherwise be available* to specific consumers.

Implications of Vocational Rehabilitation for Independent Living



Chapter Four

IMPLICATIONS OF VOCATIONAL REHABILITATION FOR INDEPENDENT LIVING

I. OBJECTIVES:

A. To highlight the implications of the state vocational rehabilitation (VR) agency services for independent living centers and programs (ILCs/ILPs)

B. To identify rationales for ILCs/ILPs to work with VR programs

C. To identify specific ways that ILCs/ILPs can beneficially utilize VR services

II. SUMMARY:

In accord with the traditional rehabilitation paradigm, VR practitioner "purists" consider IL to be but one part of the field of vocational rehabilitation. Accordingly, they suggest that the rehabilitation profession and process can contribute to successful IL outcomes. Twelve specific service areas are discussed in this chapter. Review of these twelve areas suggests that ILCs/ILPs, and the consumers they serve, can benefit from consideration of vocational needs in the planning of IL services and from establishment of collaborative linkages with the VR agency.

III. DISCUSSION:

This and the next chapter have been structured around two "pure" views of the IL/VR relationship. These views reflect the *perceptions* of many people about how the system functions. Each chapter deals with one part of the total rehabilitation system and the contribution it can make to successful rehabilitation (or habilitation) of people with disabilities. Separate discussions of the IL and VR perspectives are intended to clarify the interdependent and reciprocal relationship between IL and VR. They *are not intended* to suggest that a choice must be made between the two perspectives, or that either perspective is complete in itself. Indeed, the ultimate theme of these chapters, and the entire study, is that it would be beneficial for all if the IL and VR parts of the rehabilitation system would collaborate. Moreover, the chapters do not explore all aspects of either IL or VR services, but only those relevant to IL/VR collaboration.

Is IL a part of VR, or is VR a part of IL? VR practitioner purists assert that IL issues and services are but one part of the VR continuum. They hold that obtaining and maintaining employment is one of the most important human needs, that helping people to meet this need is a primary social goal, and that ILCs/ILPs make up but one type of the many service providers that can help in achieving this goal.

The VR perspective has been identified with the traditional rehabilitation paradigm, which is summarized on the following page. It is characterized by professionals directing treatment of a patient or client, including a focus on the individual as the locus of the problem; identification of physical impairments,

psychological maladjustments, skills deficits, and problems related to personal motivation and cooperation; resolution of problems through professional intervention; control of services by the professional(s); and achievement of gainful employment, maximum self-care, personal adjustment, and completed treatment.

Viewed from the perspective of the traditional rehabilitation paradigm, the rehabilitation profession and process suggest certain principles and offer certain services that can contribute to successful IL outcomes. This chapter portrays the hypothetical responses of a VR counselor in dialogue with an ILC services specialist.

"Why should I work with you"? asks the IL services specialist. "What does your VR system have for me? What opportunities does it offer consumers"? In response, the VR counselor suggests the 12 reasons explained below.

1. **VR services can assist consumers in achieving increased independence through evaluation and preparation for, and participation in, employment.**

   A consistent finding in surveys of people with disabilities is that the majority value employment and would like to have a job. For example, in a recent Lou Harris survey of people with disabilities that was commissioned by The National Organization on Disability, 75% of the respondents reported that they would like to work. Conversely, over 65% of those interviewed reported that they were unemployed.

   The high level of unemployment of people with disabilities compounds other problems they face. Dependency upon the public assistance programs which have been established to meet the needs of people with low incomes contributes to a loss of personal dignity and self-respect. If a person is poor, there are fewer options readily available. Lifestyle choices are often dictated more by what is possible than what is desired. Most people with disabilities have experienced frequent social rejection, accompanied by an expressed or implied message that they are "sick," "fragile," or otherwise "not able" to participate fully in family, work, and community activities. The disability and unemployment of a family member can cause added conflict and problems within the family home. Externally, the disability and unemployment of a family member can lead to a public perception of the individual and the family as a community "problem."

   A person's independent functioning can be enhanced in many ways through employment. Long-term financial problems can be resolved and the person's ability to "pay one's own way" can lead to an increased sense of dignity and self-respect. Achievement of economic independence through employment can make many more options available and empower the individual to make more lifestyle choices. Successful work status can contribute to greater community acceptance and the ability to participate more effectively in community affairs. A positive work experience can also lead to a more positive self-image, enhanced community status, and improved family stability and public image.

Comparison of the Traditional Rehabilitation and Independent Living Paradigms

Item	Traditional Rehabilitation Paradigm	Independent Living Paradigm
Role of person with disability	Patient/Client	Consumer
Role of service	Professional Prescriber & manager of treatment Controller of access to services Diagnostician	Peer Consultant and role provider model Helper and advocate Mentor
Definition of problem	Physical or mental impairment Employability skill deficits Functional limitations Lack of motivation & cooperation	Dependence on professionals, relatives, etc. Inadequate support services Architectural barriers Economic barriers
Locus of problem	In the individual with a disability	In the environment In the medical model, the rehabilitation process & the narrow "professional" attitudes they can promote
Solution to problem	Intervention by rehabilitation professional Evaluation & training Home & job site modification	Peer counseling Advocacy Self-help Consumer control Removal of community barriers & disincentives
Who has ultimate control	Professional	Consumer
Desired outcomes	Maximum activities of daily living (ADL) Gainful employment Psychological adjustment Improved motivation Completed treatment	Self-direction Least restrictive environment Productivity (social & economic)

Based on the work of several authors, including Gerben DeJong (1981, p. 31).

The focus of VR services is to help individuals achieve vocational goals. During the seventy years since its establishment, an extensive VR delivery system has been developed. It is a nationwide system that includes many skilled personnel and resources and is involved in extensive state and local networking with other service delivery systems. The system provides vocational counseling and purchases an array of needed goods and services.

The expertise of VR counselors is in helping people prepare for and obtain employment. This includes evaluation of rehabilitation potential, counseling and guidance, recruitment and training, job placement, and follow-up services. They also have case service budgets with which to purchase other goods and services needed to achieve the vocational goal, including such essential needs as housing modifications, adaptive devices, and medical restoration. These several areas of service are discussed in more detail in points 2-10.

The IL movement is committed to dealing with the individual in a holistic manner. Since employment is an important part of a person's life, the ILCs/ILPs should include consideration of vocational needs in their service planning processes. When gainful employment seems possible and is desired by consumers, it should be considered as a preferred option in dealing with long-term financial problems. Positive work experience should be considered as one possible way of dealing with problems related to low self-esteem, lack of community acceptance, low community status, and family instability.

The intrinsic benefits of evaluation and preparation for employment should also be considered by the ILCs/ILPs. Even if vocational outcomes are not ultimately achieved, the process of evaluation and preparation for employment can often result in significant benefits to the consumer in terms of increased skills and resources.

Finally, the range of skills and expertise offered by the VR delivery system should be considered by the ILCs/ILPs. Rehabilitation counseling is a recognized professional field, with standards, curricula, a defined rehabilitation process, and its status is recognized by other professional disciplines. Given the commitment of ILCs/ILPs to use their resources for consumer-driven services and peer support, it makes sense for them to seek professional VR counseling and related services from the VR delivery system. This can enable the ILCs/ILPs to focus their resources and attention upon other IL services.

Negotiating the most appropriate IL and VR roles may, however, be difficult in those situation where ILCs/ILPs employ credentialed rehabilitation counselors and establish their own formal VR services programs. Under these circumstances, use of the VR system resources may not be as advantageous for the ILCs/ILPs. It should, though, be noted that some IL practitioners express the fear that establishing their own VR resources and expertise can move ILCs/ILPs away from the peer and advocacy services which are at the core of the IL movement.

2. **VR services can assist the individual in exploring vocational options and making choices. This includes counseling and guidance as well as formal evaluation of employment aptitudes and preferences.**

Many people with disabilities who are unemployed either have no work history or developed job skills, or can no longer perform the work for which they are trained. In order to prepare for employment, they need to select and develop a saleable skill.

VR programs offer expertise in helping people assess their job aptitudes and interests, consider work options, and choose an occupational area. VR counselors are trained in providing direct counseling and guidance concerning these matters. They have access to agencies and other providers who perform aptitude and vocational testing, and resources with which to purchase such evaluations. In some instances, they are also able to assist an individual in arranging for evaluative or trial work experiences.

VR programs operating under the Rehabilitation Act of 1973 can extend the evaluation of vocational abilities and aptitudes up to 18 months before they are required to make an eligibility determination concerning employability. This provides opportunity for vocational evaluation of people with severe disabilities whose likelihood of employability cannot be quickly determined.

For IL consumers who have expressed interest in exploring vocational possibilities, the VR agencies can be a valuable resource. ILCs/ILPs should consider VR programs as the primary resource to assist consumers in exploring their vocational aptitudes and making choices.

3. **VR services can assist consumers in setting workable plans for developing vocational capacities and obtaining jobs.**

Developing vocational capacities and obtaining jobs is a complex process for most people with disabilities. It typically involves several sets of activities which must be planned and carried out over a significant period of time.

VR counselors are trained in assisting people with disabilities in developing these plans. They know the agencies and resources that can be accessed, the procedures and customary time frames involved in doing it, and the ways that the various steps can be coordinated. Their help can include developing training and educational plans, and (when no other resources are available) providing financial resources for the training or education. They can also help the consumer think through this process and make decisions concerning the available options.

For IL consumers who have decided to develop their vocational skills and obtain jobs, the VR agencies can be a valuable resource. The ILCs/ILPs should work with the VR agencies to access their services in these instances.

4. **VR services can assist in obtaining needed physical and mental restoration.**

People with disabilities frequently have physical or mental conditions that can be improved through treatment. These conditions can often limit their abilities to function more independently. Frequently, they lack insurance or other assistance needed to obtain medical, psychological, or psychiatric services to treat the condition.

VR agencies can purchase physical and mental restoration services, when not available from other sources. This includes diagnostic and evaluative services to identify the problem and prescribe appropriate treatment. By their very nature, these services can contribute to increased independent functioning in both vocational and nonvocational activities.

The ILCs/ILPs should collaborate with VR agencies concerning the possible provision of these services for IL consumers who need medical, psychological, or psychiatric treatment that is not available from other sources. If the consumers have interest in exploring current or future vocational possibilities, they should be referred to the VR agency for evaluation. If they qualify for the VR programs, at least under the provisions of an extended evaluation, they may be eligible to receive physical or mental restoration services that can have benefits in both vocational and nonvocational areas of functioning.

5. **VR services can help a person gain skills that contribute to increased independent functioning as well as employment readiness.**

People with disabilities may need to gain a variety of skills to prepare for employment. Many of these skills can also contribute to their ability to function independently in nonvocational areas. Some of the most common are communication skills, self-assurance and assertiveness, grooming and selection of clothes, getting along with other people, accepting personal instruction and criticism, maintaining schedules, reading and interpreting written instructions, policies, and procedures.

VR agencies offer a wide array of pre-employment services, including individual and group counseling, job clubs, work experience, on-the-job evaluation, and a variety of classes and training (including job seeking skills). These services can also be provided as part of a comprehensive extended evaluation.

VR services for persons who are blind also include assistance in developing needed mobility and other adaptive skills. This has traditionally been an important area of service for VR agencies/units for the blind. These services are important for employment readiness, and they are equally important for nonvocational activities.

ILCs/ILPs should consider the VR preemployment services as an important resource for their consumers who are not employed. Consumers with identified vocational goals can often derive both IL and VR benefits from these services.

Consumers who have an interest in employment but no current vocational goals can be assisted in exploring their employability and can, at the same time, develop skills that will help them function more independently in nonvocational areas of activity.

6. **VR services can assist in identifying available employment opportunities and training individuals for them.**

People with disabilities who are interested in employment not only need to obtain employment skills, but they need specific skills for jobs that are available.

VR agencies develop information systems and linkages with employers in order to identify available jobs, and skills needed for those jobs. They then work with their clientele to recruit individuals and train them. This includes arrangements with a number of resources to provide the needed training.

ILCs/ILPs should work with VR agencies to help consumers who want employment to identify available job markets they would like to access, and to undertake training to obtain the skills needed to qualify for those jobs.

7. **VR services can assist a consumer in obtaining other goods and services that contribute to enhanced independent functioning.**

An important resource of the VR agencies is their ability to purchase goods and services needed to carry out an employment plan. This is a very flexible resource that can respond to a variety of individual needs. Among the goods and services that VR agencies can provide are vocational and other training services, occupational licenses, tools, equipment, initial stocks and supplies, and transportation. In this process, the VR agencies often deal with arrangements for a variety of personal and environmental support services, including personal assistance services.

Most ILCs/ILPs do not have a general case services budget for the purchase of needed goods and services. They should, thus, collaborate with VR to access this resource for consumers who have a vocational goal. Further, they should also explore VR as a possible resource when an IL consumer chooses to seek goods or services that can be related to vocational needs. In these instances, the consumer's needs may be addressed through VR's evaluation process.

8. **The VR delivery system can assist in dealing with the strong financial disincentives which often discourage employment.**

Much attention has been given in recent years to identifying and attempting to modify the many disincentives to employment that are presented by financial and medical assistance prog ams. Despite recent improvements, the "safety net" benefits provided by Social Security, Supplemental Security Income, Medicaid, and Medicare can be significantly reduced or eliminated before an individual with a disability, seeking to move into employment, is fully prepared to meet his or her own needs. Recent legislation (Employment

Opportunities for Disabled Americans Act of 1986, P.L. 99-643; & Omnibus Budget Reconciliation Act of 1989, P.L. 101-239, Section 6012) extending the Social Security "1619 A & B" provisions, strengthening use of the Plan for Achieving Self-Support (PASS), and clarifying Impairment Related Work Expenses has removed some of the barriers to employment, but many financial and medical care barriers remain—especially during the often lengthy period as an individual transitions into a regular work situation. These disincentives not only directly affect the individual's vocational plans, but contribute to a general environment which discourages risk-taking for any purpose.

In assisting consumers to prepare for and obtain employment, the VR agencies have become very involved in dealing with these work disincentives. The VR agencies have developed expertise in a number of financial assessment and self-support plans (such as the Social Security PASS), a variety of support services, and strategies for resolving constraints imposed by public perceptions and attitudes toward people with disabilities.

In order to facilitate the effectiveness of their IL services, the ILCs/ILPs should seek involvement of the VR system in dealing with the individual's concerns and problems related to employment and the work disincentives. Significant benefits can be derived from the VR system's skills in resolving these issues, and in developing workable plans for transition to regular work. Clearly identifying and addressing these issues can, in turn, free the individual to focus more effort upon the IL needs that have been selected for action.

9. **VR services can help place an individual in appropriate employment.**

Even when people with disabilities have marketable skills, they often face a challenge in securing an appropriate job.

VR agencies offer a valuable job placement service. They work extensively with the employer community to identify and develop work opportunities for people with disabilities. VR staff have access to information about these job opportunities, and also have skill in matching individuals with placement opportunities.

In working with consumers who are seeking employment, the ILCs/ILPs should consider the VR agency as a primary placement source. The VR agency may, in fact, be the only job placement service responsive to the needs of people with disabilities in many communities.

10. **VR services provide follow-up and arrange for needed follow-along services to support successful job performance.**

For many people with disabilities, obtaining a job is but the beginning of the process. They may need a wide range of personal and community supports in order to successfully maintain their employment.

VR agencies provide initial follow-up on job placements to assure that the

consumers, and also the employers, are satisfied with the arrangements. If specific problems exist with the job or the work performance, the VR counselors can provide counseling and other services to resolve the problems.

Although VR services under the Rehabilitation Act must be time-limited, supported employment programs serve many individuals who need continuing support in order to maintain employment. The VR counselors can play a major role in arranging for continuing support by other community agencies.

ILCs/ILPs should collaborate with VR agencies in obtaining needed follow-up and continuing supports for consumers who enter employment.

11. **Providing services that can be purchased by the VR system can result in increased resources for the ILCs/ILPs.**

In addition to the specific consumer benefits already identified, VR services offer systemic benefits to ILCs/ILPs. An important systemic benefit is that the VR system has the capacity to purchase services from the ILCs/ILPs. There is a notable scarcity of resources for IL services. The VR delivery system has control of much greater resources, most of which are used to purchase goods and services needed by clients. To the extent that ILCs/ILPs can provide services reimbursed by the VR delivery system, they can increase the resources available to them.

There are many areas of need in the VR system which might best be addressed by the ILCs/ILPs. The VR system often has problems in case-finding and provision of services (including job placement) to persons in rural areas. Some VR agency clients find it personally difficult to deal with the highly structured VR process and system. Since it operates through state agencies, the VR system can find it difficult or impossible to provide effective public and legislative advocacy on behalf of their clients. Focusing on time-limited services, the VR system is not able to deal effectively with consumer needs for long-term support services. Employers require information and education about people with disabilities that can better be given by those affected (such as ILC staff and volunteers) than by the VR agency professionals. This need is one which is likely to become even more important with passage of the Americans with Disabilities Act. In these and other areas of need, the ILCs can productively develop services which will be purchased by the VR system for its clients.[4]

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[4] A corollary issue is whether the ILCs/ILPs should provide VR services for this purpose, or IL services that are supportive of VR outcomes. To the extent that they provide VR services that could be furnished by a traditional VR provider (e.g., a rehabilitation facility), their efforts may serve to increase organizational size but not the ILC's/ILP's capacity to deliver IL services or carry out its IL mission. Some IL practitioners even fear that, by putting too much emphasis on developing services that can be sold, the IL movement is in danger of losing focus on its own, unique mission.

12. **The effectiveness of IL services can be enhanced through networking with other human service delivery systems, including the VR system.**

Another systemic benefit is that of community networking. IL and VR services can often be mutually complementary, with IL services focusing on personal and environmental supports while VR services focus on vocational outcomes. All services provided through the two delivery systems are typically directed toward achievement of increased individual independence. In fact, IL and VR services often complement other human services systems, especially mental health, income assistance, social services, medical assistance, and employment systems.

Given this similarity of purpose, ILCs/ILPs should seek to enhance the effectiveness of their IL services by closely coordinating and linking with other services being received by their consumers. The result is two or more delivery systems working together to accomplish a mutual purpose.

IV. IMPLICATIONS:

Discussion of the preceding twelve issues shows clearly that ILCs/ILPs and their consumers can benefit from consideration of vocational needs and establishment of effective linkages with the VR delivery system. This will result in a more holistic response to individual consumer needs, more effective development of individual independence, and more efficient use of scarce IL resources.

Some of the benefits that can result from linkage of the ILCs/ILPs to the VR systems include:

1. Increased independence through evaluation and preparation for, and participation in, employment;

2. Assistance in exploring vocational options and making choices;

3. Assistance in setting workable plans for developing vocational capacities and obtaining jobs;

4. Assistance in obtaining needed physical and mental restoration;

5. Help in gaining skills that contribute to increased independent functioning as well as employment readiness;

6. Assistance in identifying available employment opportunities and being trained for them;

7. Assistance in obtaining goods and services that contribute to enhanced independent functioning;

8. Assistance in dealing with the strong financial disincentives which often discourage employment;

9. Help with placement in appropriate employment;

10. Help with needed follow-up and arrangements for needed follow-along services to support successful job performance;

11. Increased resources for the ILC or ILP; and

12. Enhanced effectiveness of IL services through networking with other human services delivery systems.

These benefits are, however, not uniformly available through all VR agencies. As with any human service delivery system, the VR system does not—or cannot—always do what is expected. There is variance from one locality to another, and from one state to another. This suggests that ILCs/ILPs must carefully study their local VR systems to learn what goods and services are readily available, and how to access those that are provided on a limited basis. They should further investigate the reasons that some goods and services are provided only on a limited basis, and that some may not be locally available at all. If investigation of these circumstances reveals an inadequacy of resources or other identifiable barriers, the ILC/ILP may decide to undertake public information, advocacy, and other community development activities to develop needed resources or otherwise increase options available to people with disabilities.

It must additionally be noted that there are strong forces which often predispose ILCs/ILPs to work alone, with little linkage or coordination with the VR system or other human service providers. The IL paradigm seeks a nonmedical and nonbureaucratic response to individual need. Since the VR system is traditionally structured largely around a medical model of diagnosis and service delivery, and also possesses a well-defined bureaucracy and case/service process, it is often seen as the antithesis of the IL movement.

For ILCs/ILPs to establish close linkages and collaboration with the VR system, they must be able to develop or obtain:

1. Clear delineation of appropriate roles and responsibilities for both the VR and IL systems;

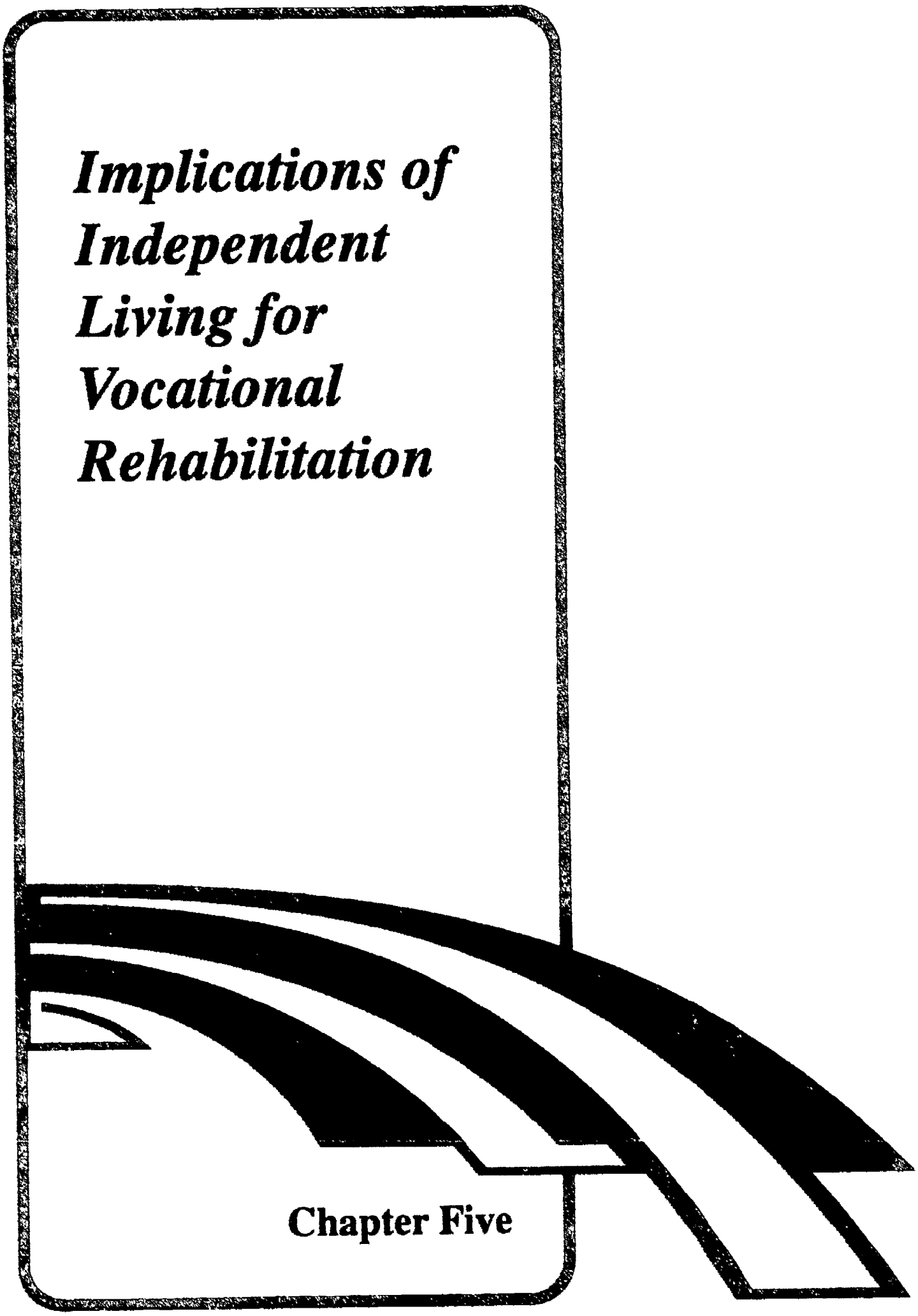
2. Assurance that consumer control of services will not be compromised by the collaborative relationship;

3. Evidence that the VR system can and will be responsive to the IL consumer and community advocacy functions; and

4. An overriding sense of teamwork that joins the IL and VR systems (as well as other involved delivery systems) in working collaboratively to help the consumer achieve his or her cultural and life style choices.

To establish a sound foundation for increased collaboration with the VR system, ILCs/ILPs should work with the VR agencies to develop these four prerequisite conditions.

Implications of Independent Living for Vocational Rehabilitation



Chapter Five

IMPLICATIONS OF INDEPENDENT LIVING FOR VOCATIONAL REHABILITATION

I. OBJECTIVES:

A. To highlight implications of the independent living (IL) movement and of IL centers and programs (ILCs/ILPs) for vocational rehabilitation (VR) agencies

B. To explore why it would be beneficial for VR agencies to work with ILCs/ILPs

C. To present ways that VR agencies can benefit from collaboration with ILCs/ILPs

II. SUMMARY:

In accord with the IL paradigm, IL practitioner "purists" consider VR as but one part of the field of independent living. Accordingly, they suggest that the IL movement and the ILCs/ILPs can contribute to successful VR outcomes. Fourteen specific relevant service areas are discussed in this chapter. Review of these fourteen areas suggests that the VR agencies and the clients they serve can benefit from consideration of IL needs in the planning of VR services and from establishment of collaborative linkages with the ILCs/ILPs.

III. DISCUSSION:

This and the previous chapter have been structured around two distinct views of the VR/IL relationship. These views reflect the *perceptions* of many people about how the system functions. Each chapter deals with one part of the total rehabilitation system and the contribution it can make to successful rehabilitation (or habilitation) of people with disabilities. Separate discussions of the VR and IL perspectives are intended to clarify the interdependent and reciprocal relationship between VR and IL. They *are not intended* to suggest that a choice must be made between the two perspectives, or that either perspective is complete in itself. Indeed, the ultimate theme of these chapters, and the entire study, is that it would be beneficial for all if the VR and IL parts of the rehabilitation system would collaborate. Moreover, the chapters do not explore all aspects of either VR or IL services, but only those relevant to employment outcome collaboration.

Is VR a part of IL, or is IL a part of VR? Many IL practitioners assert that VR services are but one part of the IL continuum. They hold that developing self-determination and control of one's life is one of the most important human needs, that helping people meet this need is a primary social goal, and that the VR agencies provide but one type of the many services which contribute to achieving this goal.

The IL perspective has been identified with the IL paradigm (see Chapter 4, page 65). It is characterized by a peer providing consultation and role modeling to

assist another consumer, including a focus on the environment with the medical model and the rehabilitation process as the locus of the problem; identification of dependencies, inadequate support services, architectural and economic barriers; problem resolution through peer counseling, advocacy, self-help, consumer control, and removal of barriers and disincentives; control of services by the consumer; and achievement of self-direction, least restrictive environment, and social and economic productivity.

Viewed from the perspective of the IL paradigm, the IL movement embraces certain principles which support ILCs/ILPs providing IL services that are frequently viewed as prerequisite to successful VR outcomes. Consistent with this perspective, this chapter portrays the responses of an ILC services specialist in dialogue with a VR counselor. The VR counselor asks, "Why should I work with you? What do your ILCs/ILPs have for me? What opportunities do they make available to my clients"? In response, the IL services specialist suggests the 14 reasons explained below.

1. **ILCs/ILPs provide an important information and referral resource for VR programs.**

   Information and referral (I&R) is a primary service of the ILCs/ILPs. Many have very sophisticated I&R resource files and inquiry processes. These address the full range of needs experienced by people with disabilities.

   VR agencies can establish linkages to make maximum use of these extensive I&R resources developed by the ILCs/ILPs. This can free them from developing their own I&R systems, and link them to a much broader range of community services than a VR-focused I&R system would access.

2. **IL skills training programs can help develop a number of skills which are needed for successful job performance.**

   Many problems which VR counselors face in helping people with disabilities get and keep employment relate to issues of self-care and interpersonal relations. These are areas addressed extensively in most IL skills training programs.

   Rather than developing separate program capacities to deal with these problems, VR systems could, when possible, purchase IL skills training provided by ILCs/ILPs. This not only makes most efficient use of available resources, but helps link consumers with other personal and environmental support services which they may need.

3. **Positive peer modeling and support provided through ILCs/ ILPs can be important factors in identifying vocational possibilities and facilitating development of an individual's motivation and vocational capacities.**

   Many VR program consumers are faced with the absence or weakness of personal support systems. ILCs/ILPs specialize in developing peer resource consultants, who are people with disabilities trained to provide personal support and consultation to other people with disabilities. In addition to their

direct consultation and support, these peers serve as powerful role models, their very behavior helping to counteract the negative images of "the disabled" that are held by many people, including many who are themselves disabled. The positive peer model may facilitate the identification of vocational possibilities that an individual might not otherwise have considered. It can also facilitate development of a person's motivation to set and achieve vocational goals and specific skills which are needed for successful vocational attainment.

To assure conditions under which the individual with disabilities will have opportunity for the personal support needed to obtain and maintain employment, VR agencies could establish linkages and service agreements with ILCs/ILPs for the provision of peer support and consultation services. The resulting provision of IL services can encourage and support the individual in setting vocational goals and securing employment, and can increase the probability that the job will be successfully maintained.

4. **IL services provide a counseling resource which can be used by VR providers.**

In addition to peer support and consultation, most ILCs/ILPs provide other counseling services. In many instances, the counseling is provided by certified, professionally credentialed staff. It is, of course, provided within the context of the consumer-controlled approach to which the ILCs/ILPs are committed.

The ILC/ILP counseling resource can often be used to advantage by VR programs. Arranging for counseling from the ILC/ILP can free the VR counselor to deal with case management demands of large caseloads. This can also provide the consumer with a more personal and (in many instances) longer-lasting counseling resource than the VR counselor can offer. It also is a way of meeting the counseling needs of those individuals who mistrust the "system" and cannot effectively be counseled by VR agency staff. As the counseling is most often provided by persons with disabilities it has other benefits such as: demonstrating to the newly disabled consumer that there is "life after disability" by personal example; access to a more active social life through center sponsored activities; and assistance in dealing with very complicated issues such as sexuality.

5. **IL services can help coordinate the resources needed by a person for development and maintenance of vocational performance.**

Many people with disabilities need a variety of personal and environmental resources in order to develop and maintain job performance. These include employment-oriented and broader family/home/community-oriented resources. For example, a person may well need vocational evaluation, pre-employment training, job coaching, personal assistance services, home location and modification, chore services, financial counseling, community transportation, and leisure activities. Coordinating these disparate resources often requires a more comprehensive case services function than many VR counselors have time or agency linkages to do.

Given their community-based nature, ILCs/ILPs are well situated to provide this type of comprehensive service coordination. The comprehensive assessments of IL needs that they conduct provide a useful foundation upon which coordination can be based. By conducting the IL assessments and helping coordinate services they can provide valuable assistance to both the consumers and the VR agencies.

6. **IL services can provide advocacy that is often essential in removing barriers and obtaining resources needed by a person for vocational performance.**

Advocacy is another of the core IL services, including both individual advocacy community (systems) advocacy. Even though VR agencies provide advocacy, there are many situations in which state rehabilitation agency staff cannot advocate as effectively. The community-based ILC/ILP often can, for example, obtain access to a community-based General Education Diploma program, or obtain accommodations from a community employer. In these situations, the VR agencies can best serve their own needs and those of their consumers by arranging for the advocacy to be provided by the ILC/ILP.

The experience of the ILCs/ILPs has demonstrated that advocacy is often an essential ingredient in obtaining needed goods and services. As a minority group within society, people with disabilities have frequently experienced rejection and denial. Many have accordingly internalized a number of negative expectations about the responsiveness of community resources to their needs. In a similar manner, many have not had opportunity to develop the assertiveness and self-advocacy skills needed to deal with the complicated bureaucratic systems and processes which they encounter. ILCs/ILPs work with consumers on long-term development of assertiveness, self-advocacy, and community leadership skills. Still, circumstances frequently arise in which people with disabilities require organized advocacy assistance to deal with immediate needs. This is where the involvement of the ILCs/ILPs can have significant and immediate impact.

It must be noted that the organizational role in advocacy is one of the significant perceived differences between the IL and VR paradigms, and one of the functions that frequently leads to conflict between IL organizations and VR agencies. While the traditional VR paradigm holds that the problem is in the individual and is to be resolved through treatment and training, the IL paradigm holds that the problem is in the environment and is to be resolved through removing physical and attitudinal barriers. For VR agencies to make use of ILCs/ILPs in providing advocacy, both parties must come to agreement concerning their individual roles, must develop respect for each others' roles, and must jointly agree that the advocacy is needed and appropriate.

7. **IL services can help to enhance consumer self-direction, which is often a crucial factor in successful job performance.**

Much attention has been given by VR programs to issues involving consumer self-direction. Individual deficits in self-direction are frequently cited as major

impediments keeping an otherwise qualified individual from obtaining a job or successfully performing the job duties.

The issue of self-direction is central to the IL movement. IL practitioners hold that decision-making and control of one's life are rights that should be afforded to every citizen, regardless of disability. Many of the IL services are designed specifically to help an individual learn the skills needed to make decisions and control his/her life. In recent years, ILCs/ILPs have been expanding these services, having success not only among those with physical disabilities but also those with cognitive impairments. The IL services strive for the highest degree of control and decision-making of which the person is capable. By seeking these services for consumers who need them, VR programs can help individuals increase their capacities for decision-making which often increases their capacities to get and keep employment.

8. **ILCs/ILPs can assist a person in developing an enhanced self concept, which is an essential factor in successfully getting and maintaining a job.**

People with disabilities not only need self-direction for successful vocational performance, but also a positive concept of self. If people do not like or respect themselves, they can find it most difficult to cope with the interpersonal demands of a job. Their relationships with supervisors, co-workers, and (where applicable) customers can be profoundly affected by their self concepts. If they think of themselves as "unworthy" and "unable", they will most likely have poor relations with others at the job site, and will most likely not perform as well as they could.

In counseling and IL skills training, ILCs/ILPs strive to improve the individual's self-concept. Much of the negative self concept held by people with disabilities is based on the negative stereotypes and messages that have previously been (and still are) promoted by society at large. The ILCs/ILPs work to overcome these negative images, both for individuals with disabilities and within society.

By accessing the services of the IL centers and programs, VR programs can obtain assistance in enhancing individuals' self concepts. Indeed, since the IL services are provided within a context of peer support and counseling, the IL services may often be more effective in this effort than services which are provided through clinics or certified therapists.

9. **IL services can help identify and address IL needs which must be met as an important precondition to obtaining and maintaining employment.**

Both VR and IL practitioners report that the difference between successfully or unsuccessfully getting and keeping a job can frequently be traced to the extent to which an individual's IL needs have been met. If the person's needs for life skills and personal care, family/peer support, home and residential environment, and community environment and support services have been met, that person is free to focus sufficient attention on the job. If, however, there are significant unmet IL needs, the person's concern and attention are diverted from

vocational issues to the more basic demands of daily living.

The VR program has traditionally focused only on needs which are directly related to vocational requirements. ILCs/ILPs often offer a comprehensive assessment of IL needs, which identifies the full array of personal and environmental support needed by a person with a disability. By working with the ILCs/ILPs to address this broader range of IL needs which must be met as a precondition to successful and long-term job performance, the VR program can increase its effectiveness in serving people with disabilities, especially those who have multiple service needs.

10. **The effectiveness of VR services can be enhanced through networking with other human service delivery systems, which can be facilitated through collaboration with ILCs/ILPs.**

IL centers and programs have ongoing contact with many community service systems and providers that have not traditionally been viewed as part of the VR system. This is especially true at the local level, where the ILC/ILP is involved in a wide variety of community development activities. For example, the ILC/ILP can be closely involved with local support groups, housing agencies, personal assistants, and transportation resources—all services that a VR services recipient may require.

This networking can be especially important in developing and carrying out transition plans for moving from school to work, nonworking to work situations, or from part-time to full-time employment. Networking is crucial in the provision and coordination of follow-up and continuing services for individuals in supported employment and similar arrangements. The ILCs/ILPs can have the mix of needed direct services in conjunction with community networking linkages to carry out these crucial transition and follow-up service assignments.

By establishing collaborative working arrangements with the ILCs/ILPs, VR agencies can have enhanced access to this full range of community resources. In many instances, VR agencies could not justify mounting their own networking initiatives with these various resources and agencies. By working with the ILCs/ILPs, VR programs can establish effective means of accessing these resources when needed, without having to establish their own networking activities or to commit added resources to them.

11. **IL services can assist VR systems in accessing more severely disabled populations.**

ILCs/ILPs tend to serve more severely disabled populations than have traditional VR systems. It is common for the ILCs/ILPs to have staff, and employed peer helpers, who can recount their own experiences in working to overcome the societal and/or personal assessment that they are too severely disabled to obtain work—other than perhaps in a sheltered workshop.

As the VR program continues with its efforts to increase services to persons with severe disabilities, the ILCs/ILPs offer a way of reaching many people who are severely disabled who want to become more independent. A collaborative linkage between VR and ILCs/ILPs can assure those consumers that the VR program is committed to needed services.

12. **IL services can help with VR program outreach and case finding in rural and urban areas.**

Outreach and case finding for VR services in some rural and urban areas can be a challenging undertaking. The complex, crowded relationships of the urban areas and the distances that must be traveled in the rural areas make it very difficult to get information to, or to receive requests for service from, those populations. In both settings there can also be a high degree of suspicion about the motives and trustworthiness of the established governmental systems.

Since they are community-based and consumer-directed, the ILCs/ILPs can provide substantial assistance to VR in reaching these consumers. Part of their role is establishing communication channels through newsletters, informational meetings, etc., with people who have disabilities in the local community. Their information and activities are usually received with less suspicion and mistrust than those of governmental agencies. Collaborative linkages between the ILCs/ILPs and the VR agencies can therefore result in outreach and case finding which could not be done as effectively by the VR agency alone.

13. **The consumer involvement principle of the IL movement can help guide consumer input into VR programs.**

Consumer involvement is a basic principle of the IL movement. The ILCs/ILPs embody this principle in the form of boards and committees which can provide responsible consumer input and representation. This consumer involvement and representation is an ongoing and integral function.

Designated state agencies operating ILR services programs under Title VII, Part A are required to include ILC representation on the State Independent Living Councils, which must be established to provide public and consumer input on the agencies' and the states' IL services and programs. The designated state agencies are also under mandate to obtain public comment and input on their state plans for VR programs under Title I. By working with the ILCs/ILPs to systematically obtain consumer input and involvement for all its services and programs, the designated state agencies and their VR programs can benefit from a level of informed consumer advice and comment which would otherwise be very difficult and costly to secure.

14. **The ILCs/ILPs can help develop enhanced consumer support for increased funding, legislative initiatives and support for VR services.**

In carrying out their consumer representation and community development functions, the ILCs/ILPs serve as a focal point around which consumer

initiatives and movements can be organized. Although these activities are perceived to be "special interest" (i.e., people with disabilities), they are cross-disability in nature and reflect consumer (as opposed to paid professional) perspectives. Such initiatives and movements can raise issues and affect public policy in ways far beyond that possible for the VR agency alone.

To deal with issues involving funding, legislative initiatives and support for VR services, the VR agency could develop strong alliances with the ILCs/ILPs. To the extent that agreement can be achieved between the VR and ILCs/ILPs concerning these issues, the advocacy activities of the ILCs/ILPs and consumers can immeasurably increase the likelihood of positive public policy action.

It must, however, be stressed that alliances between the VR and IL systems should be based on a joint commitment to obtain and communicate consumer perspectives. In some instances, the consumer perspectives will not support the actions that one or both systems expected. In other instances, the perspectives will highlight differences that do exist between the two systems. This is exactly as it should be, but it means that both IL and VR systems need to be ready to hear and respond to information and recommendations different from what they may have expected.

IV. IMPLICATIONS:

Discussion of the preceding areas of possible collaboration suggests that VR programs can benefit from consideration of IL needs in their interactions with consumers, and establishment of effective linkages with the ILCs/ILPs. This can result in a more holistic response to individual consumer needs, more successful long-term employment of individuals with disabilities, and more efficient use of VR resources.

Some of the benefits that can result from linkage of VR and ILCs/ILPs include:

1. An important information and referral resource for the VR agency;
2. Development of consumer skills needed for job performance;
3. Development of an individual's motivation and vocational capacities;
4. A counseling resource;
5. Coordination of resources;
6. Advocacy to remove barriers and obtain needed resources;
7. Enhanced consumer self-direction;
8. Enhanced consumer self-concept;
9. Satisfaction of IL needs necessary for obtaining and maintaining employment;

10. Enhanced networking with other community service systems;

11. Assistance to VR programs in accessing more severely disabled populations;

12. Help with VR program outreach and case finding in rural and urban areas;

13. Accessing consumer input for VR program planning; and,

14. Help in developing enhanced consumer support for VR services.

These benefits are, however, not uniformly available through all ILCs/ILPs. As with any human service delivery system, the IL network does not—or cannot—always do what is expected. There is, in fact, variance from one community to another, and from one state to another. This suggests that VR agencies must carefully study their local ILCs/ILPs to learn what IL services are readily available and how to access those that are provided. They should further investigate the reasons that some IL services are provided only on a limited basis, and that some may not be locally available at all. If investigation of these circumstances reveals an inadequacy of resources or other identifiable barriers, the VR agency may join with the ILCs/ILPs as well as other community agencies and organizations in undertaking public information, advocacy, and other community development activities to develop needed resources or otherwise increase options available to people with disabilities.

It must additionally be noted that there are strong forces which often predispose VR programs to avoid linkage or coordination with the ILCs/ILPs. The VR paradigm relies heavily on a medical model of diagnosis and service delivery, and also possesses a well-defined bureaucracy and case/service process. Since the IL paradigm seeks a nonmedical and nonbureaucratic response to individual need, it is often seen as irrelevant to the VR process.

For VR agencies to establish close linkages and collaboration with ILCs/ILPs, they must be able to develop or obtain:

1. Clear delineation of appropriate roles and responsibilities for both the VR and IL systems;

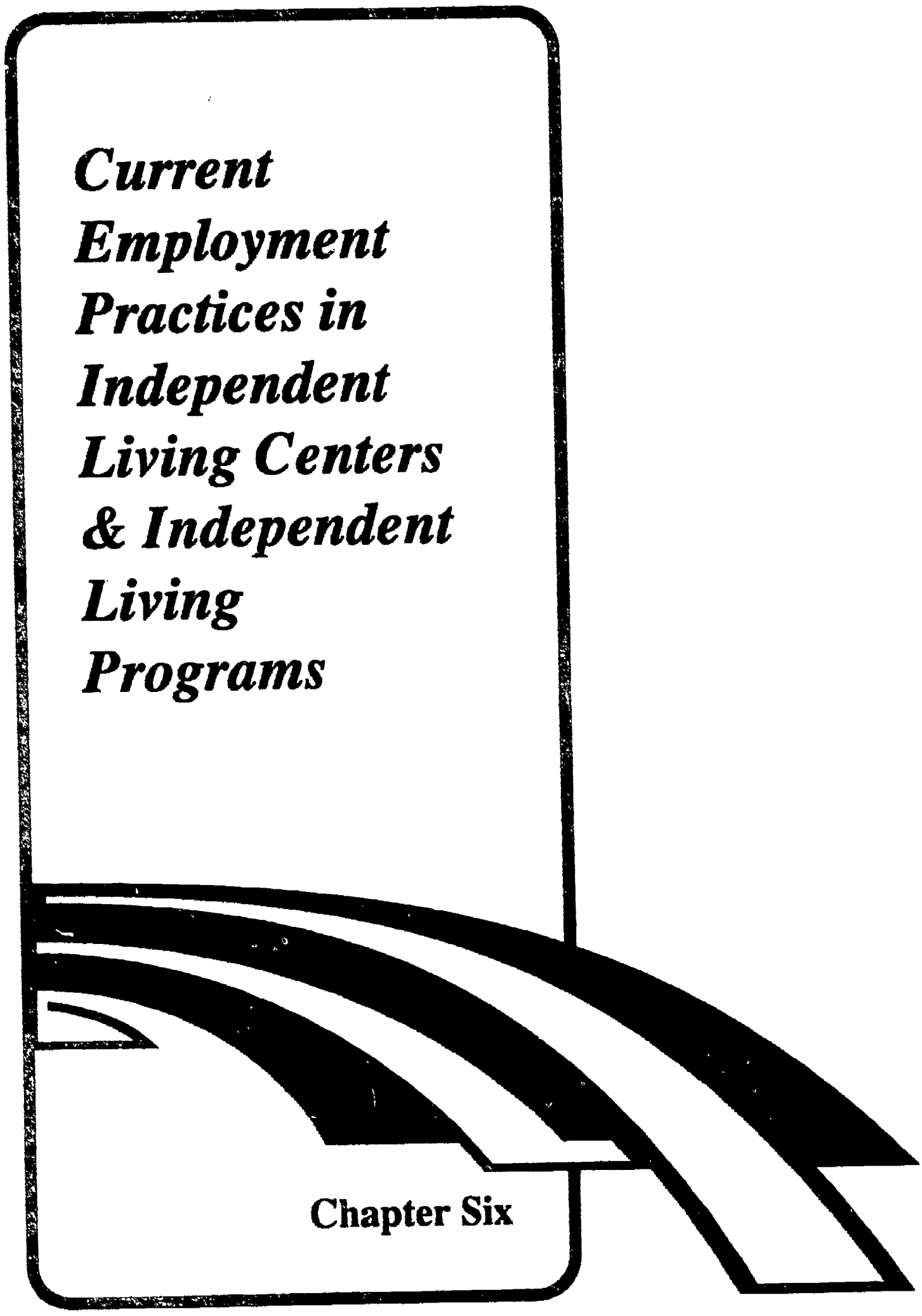
2. Assurance that the professionalism of VR programs will not be compromised by the collaborative relationship;

3. Evidence that the ILCs/ILPs can be effective in contributing to vocational outcomes; and,

4. An overriding sense of teamwork that joins VR and IL systems as well as other involved delivery systems in working collaboratively to help the consumer achieve his or her cultural and life-style choices.

To establish a sound foundation for increased collaboration with ILCs/ILPs, VR agencies should work with them to develop these four prerequisite conditions.

Current Employment Practices in Independent Living Centers & Independent Living Programs



Chapter Six

CURRENT EMPLOYMENT PRACTICES IN INDEPENDENT LIVING CENTERS AND INDEPENDENT LIVING PROGRAMS

I. OBJECTIVES:

A. To provide a statistical summary of employment activities within independent living centers and programs (ILCs/ILPs).

B. To describe the qualitative nature of employment activities of ILCs/ILPs.

C. To provide implications for future planning and services.

II. SUMMARY:

This chapter is based primarily on the results of a national survey of employment services in ILCs/ILPs (see Appendix F). The results of the survey, which is based on a 33% random sample of the population, indicate:

A. ILCs/ILPs are, in fact, significantly involved in the provision of employment services. Twenty-five percent of the ILCs/ILPs reported investing a significant amount of program resources in the provision of employment services. An additional 35% of the sample reported some involvement in the provision of employment services. Certainly, with a full 60% of ILCs/ILPs being involved in the provision of employment services, they are a resource to be considered in the planning of orchestrated employability services in any given community.

B. As this document focuses on the relationship between state rehabilitation agencies and ILCs/ILPs in the provision of employability services it is of prime importance that 26% of the ILCs/ILPs report receiving nonbase funding from state rehabilitation agencies to provide employability services. Current practices involve a considerable amount of collaboration between state rehabilitation agencies and ILCs/ILPs in the provision of employability services.

C. While the extent of employability services provided by ILCs/ILPs is relatively clear, the type and quality of employability services provided by ILCs/ILPs are difficult to determine. There appears to be a wide range in the types of employment services offered. Some of the employability programs are quite large and serve large numbers of clients, but many are rather small in terms of resources invested and numbers of clients served.

D. ILCs/ILPs report receiving nonbase funds from 20 different sources to provide employability services. ILCs/ILPs have been active in working with other community resources in the area of employability.

III. DISCUSSION:

Parameters of Chapter

This chapter focuses on the current service practices of ILCs/ILPs in the area of employment. Employment services, as defined for the purpose of this chapter, are limited to those services which are most commonly and directly associated with work preparation, work finding, and work maintenance as well as the creation of job opportunities in the labor market. The focus on employment services of a narrow definition was chosen in an effort to specifically communicate one distinct area of activity within ILCs/ILPs. This focus should not be interpreted to mean that the authors do not value and recognize the contribution to employment of those activities such as housing, mobility training, information and referral, and the many other services which more commonly fall within the realm of IL services. Certainly, career success and independence are founded on the interaction of personal achievement in all areas of functioning. It is further noted that life and career are inseparable within a holistic perspective of man—the typical perspective of ILCs/ILPs.

The provision of employment services by ILCs/ILPs is an issue in many circles. The question of whether or not ILCs/ILPs *should* provide employment services is ignored in this chapter. Suffice it, for present purposes, to say that ILCs/ILPs have the legal authority to provide employment services and in many cases do provide employment services.

Employment Services Provided by ILCs/ILPs

A very global statistical summary of the employment activities provided by ILCs/ILPs is presented in this section. The information is largely drawn from a research report (Means & Bolton, in press) reflecting the results of a national survey conducted by the Arkansas Research and Training Center in Vocational Rehabilitation (ARTCVR). The survey was designed to determine the type and quantity of employment activities provided within ILCs/ILPs.

The sample on which the information is based consists of 104 ILCs/ILPs contained in the Independent Living Research Utilization (ILRU) Directory of Independent Living Programs (Texas Institute for Rehabilitation & Research, 1989) which lists approximately 350 programs. The Directory contains listings of programs which meet the legal description for an ILC, as well as programs operated through state rehabilitation agencies and other funding sources. The ILRU Directory is considered to be the most complete source for identifying programs which provide multifaceted community-based IL services. Single service programs and administrative entities contained in the directory were omitted from the sample. The 33% sample, representing all Department of Health, Education, and Welfare (HEW) regions, 47 states, the District of Columbia, and Pago Pago is assumed to be a representative sample.

Prior to summarizing the employment activities reported by the 104 ILCs/ILPs in the sample, an "average" program represented in the sample (as determined by the arithmetical means on the different descriptive survey questions) is given. The average

program had 2.5 professional staff and 1.5 paraprofessional staff involved in direct service delivery. The average program employed one professional administrative staff member and one paraprofessional administrative staff member. Fifty percent of the staff were people with disabilities. People with disabilities comprised 65% of the board members. The average program had been in operation seven years and served a population area of approximately 350,000 within a radius of 57 miles from its location. Forty-nine percent of the populations served were in urban areas, 35% rural areas, and 30% suburban areas. The average program served 290 consumers annually. A cross-disability population was served in 93% of the settings.

Throughout the remainder of this section the extent of employment services offered by ILCs/ILPs will be referred to as being major (MA), minor (MI), or insignificant (IN). These designations were used on the survey form and the respondents were required to check one of these designations. Respondents were asked to check MA if a substantial amount of the program resources was invested in the service area; to check MI if services were provided, but were considered to be secondary or as-time-and-resources-permitted services; and to check IN if the service was not provided at all or only on rare occasions.

As can be determined by a review of the survey form in Appendix F, a number of questions concerning typical IL services were included in an effort to determine the scope of services offered by the 104 ILCs/ILPs in the sample. To further describe the overall activities of the ILCs/ILPs prior to focusing on their employment activities, the nonemployment services which were most frequently reported as major services are reported. It should be noted that the following percentages reflect only those activities perceived by the respondents to be provided at the major level. It may not be interpreted that the remaining programs do not provide these services at all. The nonemployability services which were most frequently reported at the MA level are as follows: 92% of the programs reported they provided information and referral services; 89% provided advocacy (individual, community and/or political); 87% provided IL skills training (excluding mobility training); 76% provided peer counseling/consultation; 75% provided case management services; 75% provided community support to accommodate people with disabilities (consultation on barrier removal, accommodations); and 63% provided housing services (excluding long-term residence). Again, these percentages represent each respondent's perception of the program's degree of participation in the various activities. Peer counseling, which was reported as a major service by 76% of the sample, is a core service of ILCs. It cannot be assumed that the other programs do not provide peer counseling services at all.

While a number of the survey items were oriented toward a general description of the sample, the focus of the survey was to determine the scope of activities in support of the employment needs of the programs' clientele. One question, the most general and straightforward question addressing this service area, simply asked respondents to rate the degree or amount of employment/ vocational services provided by the program. In response to this item, 26% ($\underline{n}$ = 26) stated it was a MA service, 35% ($\underline{n}$ = 35) reported this to be a MI service, and 39% ($\underline{n}$ = 39) reported their involvement in employment/vocational services to be an IN service. Clearly, a large number of ILCs/ILPs are in fact providing some type of employment services.

In addition to the more general item requesting the programs in the research sample to indicate their degree of involvement in employment services, several questions concerning specific employment services were contained in the survey. Responses indicating the extent of the provision of these specific services are provided in Table 1 (again using the MA, MI, & IN designations).

The ILCs/ILPs were also asked (questi 43 through 46 on the survey form) to respond "yes" or "no" if they provided assessme.. services, occupational skills training, formal career classes, and job advocacy activities in the community. The percentages of ILCs/ILPs that reported providing the different "types" of services under each of these questions include only those responding "yes" to the more general question. Similarly, the percentages of MA, MI, and IN ratings are based only on those responding "yes" to the major item. These questions and the results are presented in Table 2 and are followed by a brief analysis of the results. Percentages are rounded to the nearest whole.

Table 1

	Percentages*		
	MA	MI	IN
Vocational Counseling/Guidance (n = 95)	27	33	40
Placement Services (n = 96)	19	20	62
Transitional Employment Services (n = 93)	16	12	72
On-the-Job Training (n = 96)	16	17	68
Supported Work Programs (n = 96)	12	9	79
Sheltered Workshop (n = 95)	3	1	96
Work/Labor Groups (n = 91)	2	3	95
Homebound or Home-Based Employment Services (n = 95)	1	8	91

*Rounded to nearest whole number.

Table 2

Responses to survey question 43, "Do you provide any type of career/vocational assessment services?"

Yes 45% No 55% (n = 101)

Please check the types of assessment services provided by your center.

42%	Informal assessment only
18	Assessment as a part of work activity
18	Interest testing
17	Aptitude or ability testing
15	Work tolerance

Other, please list _____

_____

_____

Rate these services in terms of the explanation provided earlier.

49%	Major
42	Minor
9	Insignificant

Table 2 reveals that nearly half (45%) of the sample (n = 101) reported providing some sort of career/vocational assessment service. Nearly half of those who did provide assessment services viewed it as a major activity. In other words, one of every four programs provided assessment services as a major activity. It seems reasonable to conclude, given that nearly half of the sample provided some level of assessment services, that ILCs/ILPs are attentive to the career/vocational needs of their clientele. While the ILCs/ILPs may or may not respond with services to meet career/vocational needs, it could be assumed that, because they are assessing, they are using that information on which to base some action. Referral to an appropriate resource could be a common response made by the ILCs/ILPs.

Table 3 reveals that forty percent of the ILCs/ILPs in the sample provide some type of occupational skills training. Twenty-five percent of those providing occupational skills training (one of every ten programs) views the service as major. As will be discussed more fully later, it is expected that most of the programs utilize existing program support services (e.g., secretarial services) as opportunities to provide some clients with occupational skills training.

Table 3

Responses to question 44, "Do you provide any type of occupational skills training? (Examples: computer training, secretarial, etc.)"

Yes 40% No 60% (n = 99)

Rate these services in terms of the explanation provided earlier.

25%	Major
52	Minor
23	Insignificant

Table 4 reveals that 59% of the sample reported providing some type of formal classes or services addressing general career development. The relatively high percentage of "yes" responses to this item may be in part a result of the conceptual overlap between *IL skills* and *career skills* in the arena of personal skills. Nearly half of the programs responding "yes" to this item reported programming in the areas of lifecareer coping (46%). Job seeking classes or services were provided in 40% of the ILCs/ILPs

Table 4

Responses to question 45, "Do you provide any type of formal employability or general career development skills classes or services to increase clients' abilities (i.e., personal skills to participate in the work force)?"

Yes 59% No 41% (n = 96)

Please check the types of classes provided by your center.

48%	Basic Work Skills (e.g., punctuality, responding to supervision)
46	Lifecareer Coping (e.g., stress management, interpersonal skills, etc.)
40	Job Seeking Skills
23	Career Planning
10	Work Hardening
	Other, please list _____
	_____

Rate these services in terms of the explanation provided earlier.

51%	Major
38	Minor
11	Insignificant

responding "yes" to this question, and basic work skills were provided in 48% of the ILCs/ILPs responding yes. Half of the programs providing these types of services viewed them as major activities. Certainly a significant number of ILPs are providing services to increase their clientele's personal ability to participate in the work force. While ILCs/ILPs in their advocacy may tend to emphasize environmental factors as primary barriers to people with disabilities participating in the work force, they certainly do not ignore person variables.

Table 5 reveals that advocacy (i.e., activities to increase job opportunities) was the employment activity in which the greatest percentage of ILCs/ILPs reported participation. Seventy-three percent of the programs reported conducting these types of services and 46% of those providing the advocacy services reported these services to be a MA activity. As advocacy is a core service of ILCs, frequent participation might be expected even in the area of employment.

Table 5

Responses to question 46, "Are you involved in types of activities that are designed to increase the job opportunities in the community for people with disabilities?"

Yes 73% No 27% (n = 97)

Please check the types of services provided:

63% General/educational contact with business or industry to increase job opportunities
53 Consultation with business or industry specifically to modify work settings
41 Political initiative to create job opportunities
27 Public media messages targeting employment

Other, please list _____

Rate these services in terms of the explanation provided earlier.

46% Major
2 Minor
4 Insignificant

The ILCs/ILPs were also questioned as to whether or not they received any nonbase grant funding to provide employment or vocational services. In response to this question, 29 of 99 programs (29%) reported they did receive nonbase grant funding

to provide employment/vocational services. The reported sources of this funding are as follows:

Not only are ILCs/ILPs involved in the provision of employment services, they are apparently involved in formal contractual agreements to provide specified employment services. Twenty-nine percent of the 99 programs that responded to this item are receiving some type of nonbase grant funding to provide employment services. Some programs are receiving funding from more than one source to provide employment services. While the most common grantor of funds to ILCs/ILPs to provide employment services is the state rehabilitation agency, 19 other sources have been successfully engaged in financially supporting ILCs/ILPs to provide employment services.

Table 6

26%	from a state rehabilitation agency
4	from a private business or industry
5	from a foundation
5	from a federal government grant
8	from a state government grant (other than state rehabilitation agency)
8	from the Job Training Partnership Act
11	from other sources

Other sources reported are as follows:

4%	United Way, general funding
1	City government
1	Easter Seal Society
1	Title VII, Part A contract with Department of Human Services/Vocational Rehabilitation Services for ILC
1	Title VII, Part B ILC Grant
1	Mental Health Division - Supported Work follow-up
1	County grant
1	City, Community Action Service
1	Local fund raising
1	Fee for service
1	Vocational rehabilitation contracts
1	Department of Human Services
1	Clients

Descriptions of Employment Interventions in ILCs/ILPs

The purpose of this section is to describe the employment interventions currently being delivered by ILCs/ILPs as opposed to reporting quantitative data reflecting the extent of employability activities of the total sample as was done in the

previous section. Unfortunately, accurately describing the qualities of the employment services provided by ILCs/ILPs is impossible at this time. Research describing the nature and quality of employment interventions utilized in ILCs/ILPs has not been published. Consequently, the information in this section will be impressionistic and subjective.

The following descriptions of the employability services offered in ILCs/ILPs are primarily drawn from two sources. First, one author (as part of the national survey described previously on employability activities within ILCs/ILPs, [Means & Bolton, in press]) had the opportunity via telephone to briefly question over 80 ILC/ILP executive directors, or in a few cases their representatives, concerning their program's employability activities. Although the telephone contact was for the expressed objective of securing commitment to participating in the mail survey, executive directors were informally asked if they were providing employability services and if so, to briefly describe them. Although this particular information gathering interview was not structured, nor were interviewees' comments recorded in any systematic manner, the activity was informative and provides the basis for some tentative conclusions. Secondly, the ARTCVR is currently in process of preparing an ILC/ILP Employment Service Resource Directory (Means, in process) which contains abstracts of employment activities being conducted in ILC/ILP settings. The resource document is designed to be useful to ILCs/ILPs attempting to initiate or expand their employment services. The entries in the resource directory are being drawn from ILCs/ILPs who responded to an inquiry distributed to all ILCs/ILPs contained in the ARTCVR's ILC/ILP mailing list, which includes the ILRU Directory of Independent Living Programs (Texas Institute for Rehabilitation and Research, 1989). The employment activities described are those the executive directors were willing to share and were viewed as worthy of replication in other ILP sites. The written request asking ILCs/ILPs to submit employability activities descriptions to be included in the Resource Directory was mailed to 400 programs. Of the 400 cards mailed, 188 were returned. Of those returned, 64 responded that they (a) did, in fact, provide employment services that they felt were worthy of replication; (b) were willing to share their approach; and (c) thought it feasible for other sites to replicate their approaches. In addition to the 64 that provided employability services they felt were worthy of replication and were willing to share, 38 reported offering employability services which were either not transportable or did not merit replication. Seventy-eight programs rejected the opportunity to share their resources in the manner requested. At this writing, 20 descriptions have been prepared in draft and are available for review for this description of current practice.

Sophisticated Employability Programs Provided by ILCs/ILPs

It is the impression of the authors that only a small percentage of ILCs/ILPs that offer employability services offer sophisticated employment preparation and/or placement programs. These programs are described as sophisticated in the sense that they are complex (i.e., having an array of employment interventions) and are based on materials and procedures developed with specific instructional objectives in mind. Some of the employment programs conducted by ILPs are large service programs. One ILP reported placing over 300 people who were severely disabled per year. These sophisticated programs are probably similar (at least in service organization) in many

respects to prevocational programs that would be found in a rehabilitation facility (e.g., state rehabilitation agency, Goodwill Industries). Although these programs may be similar to conventional prevocational programs, it could be assumed that the ILC/ILP service programs serve a more severely disabled population and, at least in some instances, spring from a different philosophical base.

Example

As an example of an employability program deemed to be "sophisticated and complex," an employability program conducted by an ILP in the Southwest is described. The employability skills preparation program is within a more general service program addressing personal and social, as well as career skills. Although there is a conceptual division between program units, certainly skills such as interpersonal skills (which are taught within the social skills unit of the program) are important to the client's work performance, and it is probable that vocational outcomes are considered throughout all aspects of the program. Within this employment program, clients are assessed with standardized tests to determine current functioning level within the employability area. The assessment information serves as the basis for an individualized client skill development plan. The description of target behaviors in the employability area is extensive and each target behavior is anchored with observable behavioral indicants. Procedures for facilitating skill development in each target behavior area are specifically outlined in a trainers manual. Guidelines for assessing progress are also specifically outlined.

Within this particular Center, in addition to the formal employability skill development program, other methods that contribute to clients' career success are utilized. Clients may be referred to a local workshop when it is felt the client may benefit from such services. A work crew is maintained to provide opportunity for work experience and as a setting for refining work behaviors. ILP personnel are active in forming relationships with local employers and in the actual placement of their clientele. They report an excellent success rate (70%) in terms of placing clients who complete the employment preparation program.

This employability program is conducted in a rural area and is not a large program in terms of the number of people served (only 13 people were served last year). It is, however, deemed to be a sophisticated program in the sense that it is a multifaceted program and extensive effort went into planning the program.

More Typical Employment Services

While some ILCs'/ILPs' employment activities are similar in some respects to conventional employment preparation programs and are sophisticated, most probably are not. Again, based on the impression of the authors, it is believed that most employment services offered by ILCs/ILPs are responsive to immediate client needs (as opposed to offering a "standardized" program) and involve resources primarily dedicated to other service functions (such as having a client volunteer to help the program's support personnel for the purpose of informally assessing a person's work behavior and/or providing training to learn saleable skills). With no negative

connotation at all, many of the ILC/ILP service programs in the employment area could be described as "make-do." Such a situation is to be expected when services are added without the benefit of additional funds. Although most of these types of programs are understandably small and superimposed on other program functions, there is some evidence to suggest effectiveness.

Examples

An ILC executive director in an urban area reports that they do not have a formal and budgeted employment program, but they have found one approach to be effective. The Center's Volunteer Coordinator recruits people with disabilities from the community to provide volunteer services at the Center. The volunteers receive on-the-job training in some occupational area(s) (e.g., data entry, filing) and, hopefully, develop competence in some marketable area. A high percentage of these volunteers have transitioned into competitive employment from their volunteer positions. It is noteworthy that the majority of the people successfully participating in the program are reported to have been deemed nonfeasible for employment by the state rehabilitation services.

Supported Work Services

One type of employment service in which ILCs/ILPs appear to be significantly involved, in terms of sophisticated programming, is the area of supported work. Programs have probably developed in this area primarily because funds have been available to support them. Supported work is one area in which state rehabilitation agencies and ILCs/ILPs in many locales have found acceptable ground on which to collaborate.

Example

An ILP in an urban area has a yearly contract with the state rehabilitation agency to provide a supported work program. A predetermined number of successful placements is required to meet the contractual agreement. The ILP often refers consumers of other ILP services to the state rehabilitation agency to be accepted as clients who, in many instances, are referred back to the ILP for supported employment services. State rehabilitation agency clients who have had no contact with the ILP are also referred to the ILP for supported work services. Conventional supported work services involving placement, job coaching and follow-along are provided. One ILP staff member primarily carries out all program activities, but other ILP staff are involved during heavy client loads and/or client needs. As supported work service funding is time bound for any particular client through the state agency, the ILP may continue to provide some services to clients who have completed their supported work program under the auspices of the state rehabilitation agency.

Advocacy for Work Opportunities

Advocacy for work opportunities for people with disabilities is one employment activity in which a high percentage of ILCs/ILPs report activity. In response to the

employability survey, 73% reported that they participate in some type of activity designed to increase job opportunities. Some of the advocacy efforts reported, along with the percentage of the sample reporting activity in the area are: (a) political initiatives (41%), (b) public media messages (27%), (c) modification of work settings (53%), and (d) general educational contacts with business and/or industry (63%). Forty-six percent of the sample identified their advocacy for work activities as a major activity.

Example

One Center describes a service which provides educational presentations to prospective employers. It focuses on disability awareness, the vocational implications of disabilities, the purposes and uses of assistive/adaptive devices, and a general introduction to the concept of accommodations. Employers are introduced to disability related legislation and services which are available to them to support their employment efforts with people with disabilities. This Center also is available to conduct surveys at the work site to identify barriers (i.e., architectural, procedural, and/or attitudinal), and to consult with employers to overcome them.

IV. IMPLICATIONS:

It is a myth that ILCs/ILPs are not involved in employment services. Fully 60% of a national sample of ILCs/ILPs report some level of involvement in the provision of employment services, and approximately one of four programs reports its involvement to be at the level of a major service program. What are the implications of this level of involvement and the manners in which ILCs/ ILPs are currently involved in employment services? Some of the major implications are addressed below.

1. Twenty-six percent of ILCs/ILPs in the sample reported receiving nonbase grant funds from the state rehabilitation agency to provide employment services. Although no qualitative measures of the outcomes of these collaborative relationships are available, it could be assumed that some of these models are working in the best interests of people with disabilities in the community. These joint programs should be evaluated and descriptions made available to other ILCs/ILPs. Certainly state rehabilitation agencies and ILCs/ILPs in any given community should explore how they might work together more effectively to better serve their clientele, because collaboration is possible.

2. The ILCs/ILPs in the sample have been successful in securing nonbase funds to provide employment services from 20 different sources. Given the limited base funding of ILCs/ ILPs and the need for employment services, these and other sources of support might well be explored.

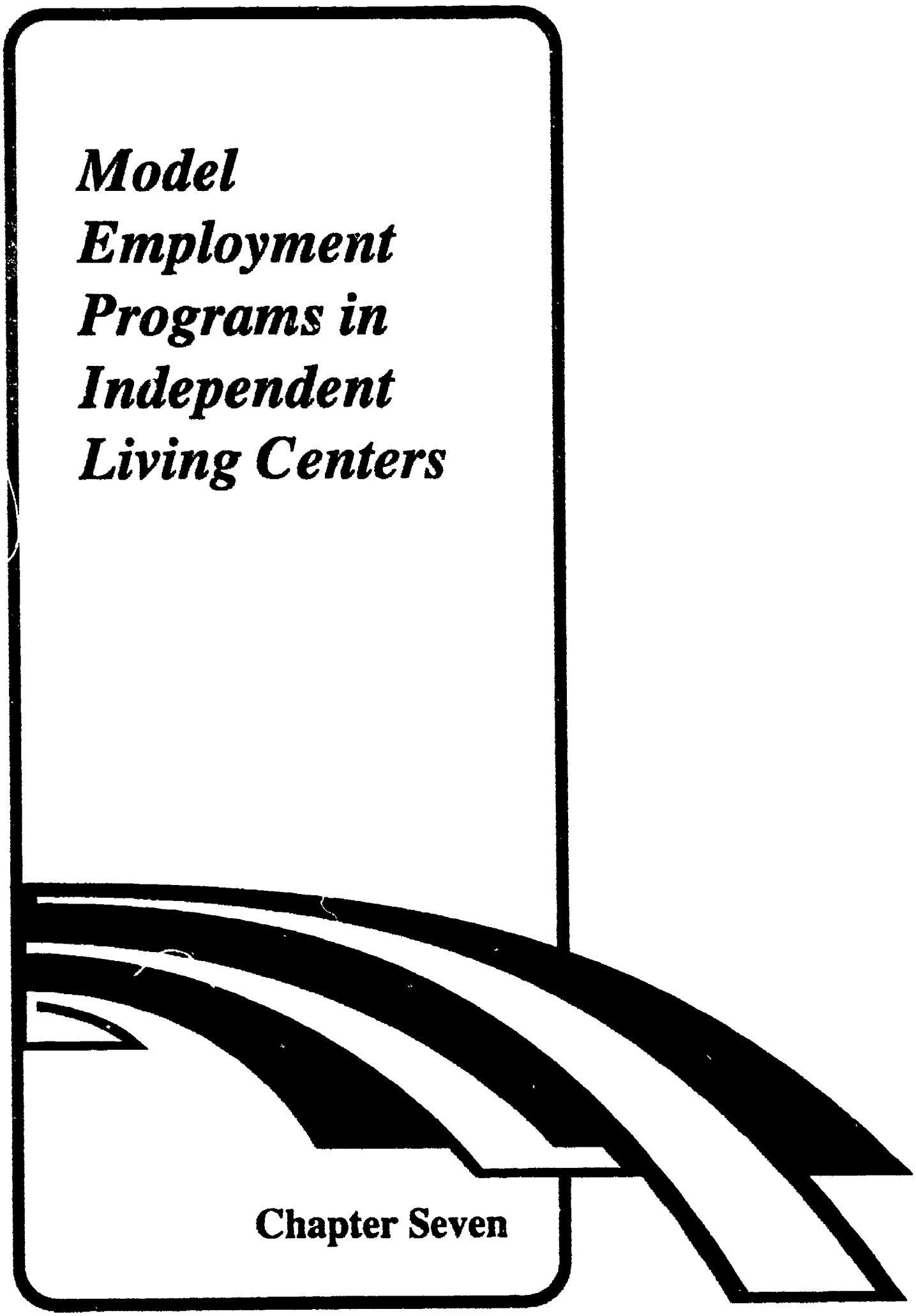
3. Within their IL services, ILCs/ILPs certainly serve a population of people who are severely disabled. There is some indication that those ILCs/ILPs that provide employability services do so to people who are more severely disabled

than those who typically receive services from state rehabilitation agencies and other agencies primarily addressing employment goals. Perhaps ILCs/ILPs could be particularly useful and effective in collaborating with other entities to provide employability services to people with severe disabilities.

4. One barrier to providing any type of service is geographic. Eighteen percent of the survey sample served only rural populations. Over 50% of the programs stated that 35% to 100% of their clients were located in rural areas. Some ILCs/ILPs have satellite services in rural areas. Given the geographic barriers that the state rehabilitation agency counselors face in locating and serving clients in rural areas, there appears to be a unique opportunity for collaboration in some rural geographic areas.

ILCs/ILPs are significantly involved in the provision of employment services despite many barriers. Even in the face of extremely low levels of funding and an overwhelming array of unmet needs in most communities, the employment needs of people with disabilities are selected by the majority of ILCs/ILPs for service responses. Although no empirical data exist to support the effectiveness of the employment services provided by ILCs/ILPs, it may be concluded that they perceive their contributions to their consumers' employment needs to be effective as they continue to provide employment services. Similarly, it may be assumed that those entities that have contractual arrangements with ILCs/ILPs to provide employment services are satisfied with the programs' performance. There certainly appears to be much opportunity for different community entities, including ILCs/ILPs, to collaborate in the provision of services which support the achievement of independence on the part of people with disabilities.

Model Employment Programs in Independent Living Centers



Chapter Seven

MODEL EMPLOYMENT PROGRAMS IN INDEPENDENT LIVING CENTERS

I. OBJECTIVES:

A. To present descriptive information concerning the independent living centers (ILCs) in which vocational rehabilitation (VR) services are provided.

B. To present model employment programs that are representative of different strategies, resources, and geographical settings.

C. To provide contacts for accessing additional information concerning the programs discussed.

II. SUMMARY:

There are approximately 200 ILCs in the United States funded through Title VII of the Rehabilitation Act. In addition, a number of other centers are funded through a variety of other resources such as State General Revenue Funds. Typically, the latter funds are appropriated to state rehabilitation agencies and subsequently contracted to cross-disability consumer organizations for the establishment and operation of centers.

Virtually all of these centers offer core independent living services such as information and referral, advocacy, IL skills training, and peer counseling. Beyond these core services, how-ever, considerable diversity exists in the services offered by centers. Moreover, in recent years, an increasing number of centers have begun offering VR services as a part of their overall programs.

The specific VR services and the manner in which they are provided vary significantly; however, the ultimate objective is the same—to enable individuals with severe disabilities to enter and maintain employment. This is consistent with the mission of ILCs in that earnings from paid employment often open avenues for IL that are difficult to achieve any other way. Similarly, the increase in self-confidence that often results from successful performance in a job augments the skills and attitudes necessary to live independently.

The model programs discussed represent a variety of approaches to providing VR services. Moreover, ILCs themselves vary significantly. Geographically, they vary from densely populated urban areas to large, sparsely populated rural areas. Some utilize new, innovative strategies for service provision while others rely on more traditional approaches to assisting individuals with disabilities in securing and maintaining employment. The programs represent different geographical regions of the country and vary in terms of financial and staff resources available for service provision. These variations are intentional in order to provide diversity in the models presented.

III. DISCUSSION:

Because of the number and diversity of ILCs that provide some type of VR services, no attempt is made to report all of the many variations that currently exist. The models described are merely representative examples of that diversity. The descriptions of the model programs were obtained by personal correspondence and/or contact with the center directors or their representatives.

Austin Resource Center for Independent Living (ARCIL)

General Description of the Center

ARCIL was established in 1980 as a cross-disability, consumer-directed ILC with Title VII, Part B, funds contracted through the Texas Rehabilitation Commission. Located in Austin, Texas, it serves a primarily urban population area of approximately 750,000.

The Center has grown considerably since its inception utilizing a wide variety of funding sources. These include State General Revenue Funds contracted through the Texas Rehabilitation Commission, Developmental Disabilities Funds, City of Austin and Travis County Funds, Community Development Block Grant Funds, contract funds through the Texas Department of Human Services and the Texas Commission for the Blind, National Institute on Disability and Rehabilitation Research grant funds, and private donations and endowments. The total annual budget for the Center is approximately $500,000.

ARCIL offers a wide range of IL services, including both basic core services (advocacy, information and referral, peer counseling, and IL skills training) and services designed to meet the special needs of the community. The latter include transitional residential services, a specialized program focusing upon assisting young persons with disabilities to transition from school settings to other activities in the community, coordination of personal assistance services, etc.

Scope of Vocational Rehabilitation Services

Vocational services are considered an integral part of the Center's total program and are coordinated closely with other service components. The Center uses a number of VR strategies including supported employment, employment skills development (classroom training), employment counseling, job placement, and follow-along to assure appropriate adjustment to the job. Additionally, the Center operates a transitional residential program for individuals with severe physical disabilities that includes personal assistance services. This latter program is available for use by consumers who are pursuing vocational goals.

Supported Employment Program

The Supported Employment Program operated by ARCIL is one of the Center's more unique programs. Administered in conjunction with Southwest Educational

Development Laboratory in Austin, this program is funded through the National Institute on Disability and Rehabilitation Research. Its purpose is to develop a national model for supported employment and IL.

The basic premise of this program and one of its unique features is the fact that it is closely integrated with all other IL services of the Center. The vehicle through which this is accomplished is the IL plan. Supported employment is viewed as one of the many service options in the Center's repertoire and is incorporated into the IL plan along with other IL services that may be necessary for a given individual.

The Supported Employment Program utilizes $63,000 per year in National Institute on Disability and Rehabilitation Research (NIDRR) funds contracted to ARCIL from Southwest Educational Development Laboratory. This funds two full-time employment advocates. The goals of the program are to serve a minimum of eight and a maximum of sixteen individuals with very severe disabilities. Visual disabilities, mental retardation, mental health disabilities, and physical disabilities are target groups for the program. An employer business advisory board is an important feature of the program and a major objective is to identify nontypical jobs for participating consumers. ARCIL is committed to providing the necessary long-term support for program participants.

Briefly stated, the steps in providing supported employment/IL services at ARCIL are as follows:

- referral/application/intake
- orientation/peer counseling
- needs assessment
- IL plan development
- IL plan implementation
- supported employment job development
- meet general/specific prerequisites for supported employment
- placement/on the job training
- assessment of IL plan
- revision of IL plan
- ongoing service/case management

In carrying out these steps, ARCIL extensively uses the job club approach. The first phase of job club services involves vocational exploration and includes visiting and observing jobs in the community. The second phase of job club services is more individualized and focused. Specific jobs are targeted and mock interviews are utilized. After job development has occurred, situational assessment is conducted at the job site and task analysis of job duties is conducted. Job coaching is utilized on either a one-to-one or a one-to-two (job coach to consumer) basis. Finally, after the consumer is functioning in a job, the third phase of job club services is utilized to assist with ongoing individualized needs (buying clothes, development of a will, etc.).

Other Employment Programs

In addition to the supported employment/IL model program, ARCIL operates other VR programs. As noted above, the five-bed transitional residential program operated by ARCIL is certified by the Texas Rehabilitation Commission to provide both VR and IL services to consumers. Personal assistance services, while consumers are receiving services through this program, are provided through a contract with the Texas Department of Human Services. Basic support for the program is derived primarily from fees-for-service through the Texas Rehabilitation Commission (VR funding; Title VII, Part A funding; and State General Revenue Funding). As in all programs at ARCIL, this program component is consumer-managed and staffed.

The other major employment programs at the Center include a continuum of vocational services. These include employment skills development, employment counseling, job placement, and follow-along to assure appropriate adjustment to the job. These services are more traditional in nature and the employment skills development component involves both day and night classes. This portion of ARCIL's program assists approximately 50 new consumers per year in obtaining employment in the community.

Relationship with State Rehabilitation Agencies

ARCIL maintains an excellent working relationship with both VR agencies in the state (the Texas Rehabilitation Commission and the Texas Commission for the Blind). Both Title I and Title VI, Part C funds are utilized to purchase VR services such as job coaching. During the Fiscal Year 1989, ARCIL served a total of 114 clients of the state/federal VR program (97 clients of the Texas Rehabilitation Commission and 17 clients of the Texas Commission for the Blind).

Additional Information

Further information may be obtained from:

Austin Resource Center for Independent Living
5555 North Lamar, Suite J-125
Austin, TX 78751
512/467-0744.

Community Service Center for the Disabled (CSCD)

General Description of the Center

CSCD is a consumer-directed, cross-disability ILC in San Diego, California. It provides a broad range of IL and vocational services to individuals with disabilities in the San Diego area. In Fiscal Year 1989, the Center served 1,908 individuals in the greater San Diego area, 784 of whom were first-time consumers. During the past five

years, CSCD has provided services to more than 10,000 individuals with 1,053 individuals assisted in securing employment.

Approximately 56% of the Center's income is derived from governmental grants and contracts and the remainder is derived from individual and corporate donations, foundations, and earned revenues. It is significant to note that, of the government grants and contracts received by the Center, only slightly more than 6% were Federal, with more than 47% coming from the State of California.

CSCD provides five basic core services as required by California law. The core services are intake and referral, advocacy, personal assistance service, housing assistance, and peer counseling. In addition, the Center provides transportation services, community living services, employment services, and durable medical equipment sales and repair services. The latter service is operated as a business and in FY 1990 achieved total sales of $297,860 while serving 1,286 customers.

Scope of Vocational Rehabilitation Services

The Center has maintained a strong vocational program since 1978 and has utilized a variety of funding resources for that effort. In past years, this included Innovation and Expansion Grants and Comprehensive Employment Training Act (CETA) funding. In recent years, the primary funding sources have been the Easter Seal Society and the California Department of Rehabilitation.

Vocational programming is primarily focused upon Job Club services, job seeking skills training, and job placement. During FY 1989, CSCD helped 282 consumers secure permanent employment at an average wage of $6 per hour.

A significant feature of the program is that consumers who are not sponsored by the California Department of Rehabilitation may receive employment services at no cost to the individuals served. Funding for that service is primarily through the Easter Seal Society.

CSCD integrates its employment services with other IL services available through the Center. While any of the available services may be utilized as needed, financial benefits counseling is a particularly significant part of the Center's employment program. Extensive use is made of the Social Security Administration's programs such as Plans for Achieving Self Support (PASS). This feature is important in allowing individuals to maintain necessary supportive services while receiving entry level wages.

Job coaching and other related supported employment services are not utilized; however, the Center makes strong use of peer modeling in its employment program. Whenever possible, individuals who provide employment services have disabilities and the Center also hires consumers for other positions in the Center to the degree possible. It is felt by Center administrative staff that modeling graphically represents the employment abilities of people with severe disabilities and is an asset in the job placement process.

Relationship with the State Rehabilitation Agency

CSCD maintains an effective working relationship with the California Department of Rehabilitation. The majority of referrals to the Center's Employment Program come from that source and the remainder come from a wide variety of other sources. It is significant to note that individuals referred to the program by the California Department of Rehabilitation are funded on an outcome basis. That is, payment for services is based upon successful placement in employment of consumers referred to the program.

Additional Information

Additional information may be obtained from:

The Community Service Center for the Disabled
1295 University Ave.
San Diego, CA 92103
619/293-3500.

New Vistas Independent Living Center (NVILC)

General Description of the Center

NVILC is a consumer-directed, cross-disability ILC that is based in Santa Fe, New Mexico, and serves nine counties in northeastern New Mexico. A wide range of IL services is offered, including IL skills assessment, IL skills training, attendant training, attendant management training, counseling, interpreter services, peer support services, and peer counselor training. These services are augmented by advocacy and information and referral as needed. The Center provides services in both urban and rural environments.

Scope of Vocational Rehabilitation Services

The Center offers a wide range of vocational services. These include general vocational evaluation, clerical evaluation, on-the-job evaluation, skills training in clerical areas, on-the-job training, vocational exploration services for individuals who are deaf, job readiness training, supported employment readiness assessment, supported employment readiness training, situational assessment, follow-along services, and job coaching. These services are provided on a fee-for-service basis.

While some of the vocational services offered by NVILC are provided in urban settings, a recently developed, major program component focuses upon the provision of vocational services in five rural New Mexico counties. This rural employment initiative has met with excellent success. Consumer service statistics virtually doubled during the first six months of FY 1989 as compared to the previous fiscal year. During that six month period, nine consumers were placed in education/training programs; 26 were placed in on-the-job training situations; 14 were placed in competitive employment; and

12 were involved in follow-up services after employment.

In addition, the Center has established community action groups in these rural areas. The groups have been very active in accessibility issues and have completed community business accessibility studies in conjunction with city councils. This effort has developed a closer liaison with the business community and has enabled Center staff to assist local businesses in job site modification while enhancing awareness of disability related issues.

Relationship with the State Rehabilitation Agency

NVILC maintains a close working relationship with the New Mexico Division of Vocational Rehabilitation (DVR). This close working relationship is represented by the fact that approximately 85% of the referrals for vocational services are from the New Mexico DVR. Moreover, a key feature of the Center's vocational program is maintaining close communication with the referring vocational rehabilitation counselor during the entire service process.

Additional Information

Additional information may be obtained from:

New Vistas Independent Living Center
2025 South Pacheco, Suite 105
Santa Fe, NM 87501
505/471-1001

Independent Rehabilitation Program of the Michigan Commission for the Blind

General Description of the Center

The legislation that created the Michigan Commission for the Blind in 1978 mandated the provision of IL services. Modest state and federal funds were made available to establish initial programs for the provision of IL services. Basic services provided through this program include skills training (communication, meal preparation, travel, and activities of daily living), low vision services (evaluation, aids, and training), hearing services (evaluation, aids, and training), information and referral, case management, peer support services, and family services.

Services are focused upon individuals with visual impairments; however, many individuals served through the program have multiple disabilities. Consumer involvement is viewed as a hallmark of the program. The program serves urban areas such as Detroit and Lansing and very rural areas such as the upper portion of the Michigan lower peninsula.

Relationship with Vocational Rehabilitation Services

A significant activity in the mid 1980s set the stage for an interrelationship between VR services and IL rehabilitation services provided by the Commission for the Blind. At that time, the Commission revised its mission statement: "...to provide opportunities to individuals with visual handicaps to achieve employability and/or function independently in society."

The articulation of that mission defined the working relationship between the VR program and the IL program in the Michigan Commission for the Blind. Currently, in those portions of the state where IL services are available, consumers referred for services have essentially two tracks. Those interested in employment receive services from the VR unit and those who need IL services receive services through the IL rehabilitation unit.

While the existence of two service tracks within an agency is not particularly unusual, the interrelationship between the two programs is what establishes the service effectiveness of the effort. Referrals are made back and forth between the two units as IL and VR issues are addressed, and the resources of both units are utilized to meet the needs of the consumer.

Scope of Relationship with Vocational Rehabilitation Services

By having services housed in the same agency and committed equally to VR and IL, resources can be marshaled in the most effective manner to meet client needs. The key to the effectiveness of this program is the fact that the consumer is the focal point for both units and services are provided from both units to meet identified needs.

Additional Information

Additional information may be obtained from:

Michigan Commission for the Blind
Saginaw State Office Building
411-G East Genesee
Saginaw, MI 48607
507/771-1765.

Wyoming Independent Living Rehabilitation, Inc.

General Description of the Center

Wyoming Independent Living Rehabilitation, Inc. is a consumer-managed, cross-disability ILC that opened in 1980 utilizing $200,000 in Title VII, Part B funds from the Wyoming Division of Vocational Rehabilitation. This funding has remained constant on an annual basis and has been augmented by approximately $160,000 per year in Title VII, Part A funding. Staff include three administrative staff, three full-time counselors, five part-time counselors, and one resource development person.

The majority of the area served by the Center is very rural and, in order to better serve consumers, counselors are stationed in strategic locations throughout the state such as Casper, Cheyenne, and Worland. Services include information and referral, advocacy, peer counseling, and IL skills training. The latter service is provided only on a one-to-one basis rather than in group settings because of the rural nature of the state. It is significant to note, however, that the two services provided most often involve assistance in obtaining adaptive equipment and environmental modification. Consumers assist in paying for the services if possible while the Wyoming Division of Vocational Rehabilitation also sponsors some of these services. The Center serves from 200 to 250 consumers at any one time and between 350 and 425 consumers are served each year in all programs operated by the Center.

Scope of Vocational Rehabilitation Services

The Center provides job coaching services through a contract with the Wyoming Division of Vocational Rehabilitation. Although the basis of this service is an administrative agreement, the key to service provision is a close working relationship between the Center and local VR counselors. Job coaches are employed by the Center to provide services to the clients of the Wyoming Division of Vocational Rehabilitation. The DVR counselor is involved in locating appropriate job coaches and negotiating rates of payment. The Center provides job coaching services for 12 to 15 individuals through this contract per year.

Relationship with the State Rehabilitation Agency

As noted from the description of VR services above, the Center maintains a close working relationship with the Wyoming Division of Vocational Rehabilitation. Service delivery is viewed as a joint partnership with both entities contributing expertise and resources to meet the needs of individuals with disabilities.

Additional Information

Additional information may be obtained from:

Wyoming Independent Living Rehabilitation, Inc.
2246 South Center, Suite 16
Casper, WY 82601
307/266-6956.

Washington Coalition of Citizens with Disabilities

General Description of the Center

The Center is located in the Seattle area and focuses upon the Puget Sound area. Its funding consists of approximately $250,000 per year in contracts, primarily from the City and County, augmented by approximately $20,000 per year from United Way. It

has three full-time staff and two part-time staff. Five volunteers provide services on a regular basis and as many as 50 volunteers are utilized on a less regular basis.

Services provided include information and referral, advocacy, employment assistance, community education and technical assistance, accessibility reviews, rights and benefits counseling, peer counseling, and IL skills training. Center services are provided to approximately 1,000 people per year.

Scope of Vocational Rehabilitation Services

The Washington Coalition of Citizens with Disabilities operates several vocationally related programs for individuals with disabilities. The Center does direct placement in employment and provides follow-up services to assure appropriate adjustment to the job. This is augmented by a job club operated by the Center and results in approximately 40 individuals with disabilities being placed in employment each year. One of the unique features of the program is that it is funded through a contract with the City of Seattle.

An innovative program operated by the Center focuses upon developing leadership and assertiveness skills in women with disabilities who are attempting to enter the world of work. Its purpose is to build appropriate self-confidence in women with disabilities in order to enhance their abilities to function in the workplace. This program is operated through a contract with King County.

Another vocational program initiated by the Center focuses upon providing consulting and technical assistance services for individuals with disabilities entering self-employment. This program has been sufficiently successful that it has been subsequently organized as a separate for-profit corporation and continues to operate in that capacity.

One of the Center's most successful vocationally related activities has been an annual meeting of employers, consumers, professionals, and vendors that is entitled "Workfest." It is done jointly with the Washington Division of Vocational Rehabilitation and other organizations in the community. It provides a forum to discuss employment related issues for persons with disabilities and is organized around a central theme that is different each year.

Relationship with the State Rehabilitation Agency

The Center works closely with the Washington Division of Vocational Rehabilitation in virtually all of the employment related activities described above. The Center has a referral relationship with the state agency and the two agencies work jointly in the development of the Workfest activity. The Center also assists the Washington Division of Vocational Rehabilitation in assessing the needs of consumers who are clients of the agency and are considering entering self-employment.

Additional Information

Additional information may be obtained from:

Washington Coalition of Citizens with Disabilities
3530 Stoneway North
Seattle, WA 98103
206/461-4550

Queens Independent Living Center

General Description of the Center

The Queens Independent Living Center was established in 1985 as a cross-disability, consumer-managed ILC. It focuses primarily upon the provision of services to individuals with disabilities in the Queens Borough of New York City. The total budget for the Center is approximately $500,000 per year. This includes state funds contracted through the Office of Vocational and Educational Services for Individuals with Disabilities (the state/federal vocational rehabilitation program) and grant funds from the City of New York designated for advocacy services.

The Center serves all disabilities; however, the largest disability populations are individuals with developmental disabilities and mental health disabilities. The Center has 15 full-time staff positions and provides a wide variety of services including advocacy, peer counseling, information and referral, IL skills training, minority outreach services, deaf services, housing assistance, benefit counseling, and work incentive training for consumers in supported employment programs. The Center serves a total of approximately 1,000 consumers each year.

Scope of Vocational Rehabilitation Services

The Center operates a unique employment related program through funding from the Office of Vocational and Educational Services for Individuals with Disabilities. The purpose of the program is to provide work incentive training for consumers, families, and professionals involved in supported employment programs and it covers all five boroughs in New York City. The unique feature about the program centers around the fact that it does not provide job coaching or other usual supported employment services. Instead, it provides training and consultation services to assist consumers, families, and professionals in dealing with work disincentives, financial issues, etc. that often cause difficulties when individuals with severe disabilities attempt to work.

Relationship with the State Rehabilitation Agency

The Queens Independent Living Center maintains a close working relationship with the Office of Vocational and Educational Services for Individuals with Disabilities

in New York as evidenced by the above referenced supported employment/work incentive training project. A close working relationship between the two entities is viewed as essential to the success of the project.

Additional Information

Additional information may be obtained from:

Queens Independent Living Center
140-40 Queens Blvd.
Jamaica, NY 11435
718/658-2526

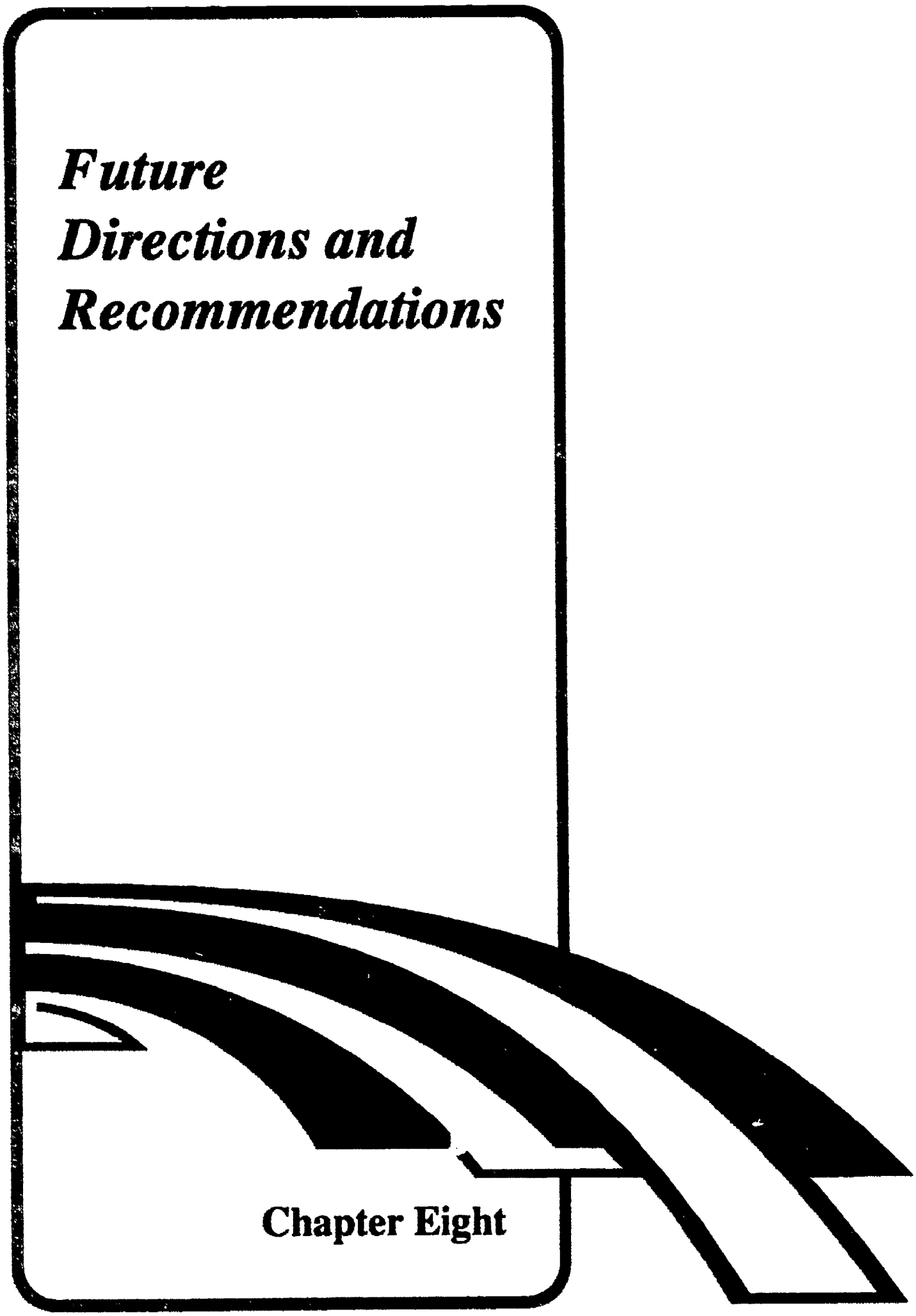
IV. IMPLICATIONS:

From the models presented in this chapter, two major implications appear evident:

A) ILCs can be effective providers of VR services. Employment is an effective means of achieving IL objectives for the consumer. ILCs, because of their flexible, consumer-focused nature, can provide a wide range of effective vocationally oriented services as well as other supportive services to enhance the consumer's ability to function in employment.

B) It is equally evident from the models presented that an effective working relationship between ILCs and state VR agencies can enhance the effectiveness of both organizations in meeting the employment and IL needs of consumers. Both organizations have particular expertise, resources and techniques that, when coordinated with the best interest of the consumer as a focal point, can result in effective vocational programming.

Future Directions and Recommendations



Chapter Eight

FUTURE DIRECTIONS AND RECOMMENDATIONS

I. OBJECTIVES:

To report opinions of recognized leaders in vocational rehabilitation (VR) and independent living (IL), information gleaned from professional literature, and the findings and conclusions of the prime study group concerning:

1. Major factors and likely trends relevant to the involvement of IL centers and programs (ILCs/ILPs) in VR services, and

2. General recommendations for the future, including the proposal of a new rehabilitation paradigm.

II. SUMMARY:

An informational base for this chapter was established through two methods. First, a review of the literature pertaining to joint VR and IL employment services was conducted. Second, interviews were held with ten administrators (see Appendix E) in the fields of VR and IL. These people were interviewed due to their familiarity with both the VR and IL systems. Major factors relevant to ILCs'/ILPs' involvement in VR services and likely future trends were then identified on the basis of the literature search and leadership interviews.

After this information base was established, the prime study group reviewed it in light of the findings and conclusions reflected in previous chapters. This resulted in a series of recommendations, ranging from relationships of the "front-line" service providers to those addressing high-level administrative actions and policies. Finally, to give the recommendations a more integrated focus, the prime study group proposed a new service paradigm.

III. DISCUSSION:

There are many historical, procedural, organizational, personal and other factors involved in the successes and failures of service providers in different communities being able to orchestrate their services in the best interest of their consumers. As they need to be understood prior to planning the future, some of the major factors relating to these divergent outcomes have been examined.

The state-of-the-art presents much diversity in the manner and degree in which VR services are being provided by ILCs/ILPs. There is also diversity in how state rehabilitation agencies and ILCs/ILPs relate. Some ILCs/ILPs and state rehabilitation personnel have developed strong working relationships and appear to be working toward true partnership arrangements. Other ILCs/ILPs have developed separate vocational programs that involve state agency rehabilitation personnel only minimally, typically in some type of referral arrangement. Still other ILCs/ILPs appear to have

taken the position that VR services fall under the purview of the state rehabilitation agency and avoid VR services beyond referral to the rehabilitation agency.

The diversity has been compounded by the role of state rehabilitation agencies in the direct provision of IL services. Many have developed IL services separate from the community-based ILCs/ ILPs and are providing IL rehabilitation services delivered by professional rehabilitation staff. The state rehabilitation agencies may use Part A funding as simply another source of service dollars and involve ILCs/ILPs only minimally. Perceptions on the part of many ILC/ILP staff that Part A funds should be clearly designated for service delivery through IL service providers rather than through state rehabilitation agencies have been a source of friction in some geographic areas. In some states, however, there are state dollars allocated for the purchase and coordination of IL services which often allows both rehabilitation agencies and ILCs/ILPs to provide a greater array of services to a larger number of consumers.

Working relationships between state rehabilitation agencies and ILCs/ILPs are frequently conflictive. The vestiges of the adversarial relationship that developed between consumers who began the IL movement and rehabilitation professionals continues to linger and to exert a negative influence on potential collaborative endeavors. There have been attempts at the national level to address this issue. However, at present no national policy initiative has been formulated to encourage closer collaboration between these entities. With the impending legislative action on the reauthorization of the Rehabilitation Act currently an issue of common concern to both VR and IL staff, better communication has begun. This may offer hope for enhanced working relationships in the future.

Although positive steps are being taken, a majority of the people interviewed for this chapter indicated that there are still many significant philosophical differences between VR and IL when viewed on the whole. Many rehabilitation agency counselors still view their clients largely in terms of their vocational potential without considering IL needs. Even those counselors who wish to move toward a more long-term and holistic approach to serving their clients are faced with case closure mandates and other obstacles.

The literature documents differences between the VR profession and the IL movement. DeJong (1979), in his seminal work on IL, contrasted VR professionals—whose views have traditionally been shaped by legislative language regarding vocational goals—and their counterparts in IL—whose views have been shaped by diminished opportunities to participate fully in community life irrespective of vocational goals or potential. This contrast in approach was perceived by Gliedman and Roth (1980) as a potential detriment to effective delivery of services. More recently, Berkowitz (1987) reviewed the philosophical differences between the VR program's approach to rehabilitation and that articulated by proponents of the IL approach. His review illuminated conflicting aspects that may interfere with effective cooperation between these service components on an agency level as well as an individual provider level.

Conflicts in terms of basic "models" (or "paradigms") between the VR and IL programs have been predisposed by their individual histories. The early VR program began as a vocational training program for World War I veterans who were disabled and then progressed to a service program providing physical restoration, counseling, and training services to eligible people with disabilities (Rubin & Roessler, 1987). By contrast IL is a grass-roots advocacy movement with the expressed intent of increasing self-direction and opportunities for active community participation of people with disabilities (Frieden, Widmer, & Richards, 1982; Varela, 1983). The VR program relies on a medical-like approach to disability in which trained counselors evaluate (diagnose) need and through the provision of professional services eliminate, reduce, or circumvent (treat) the vocational limitations (handicaps) caused by the disability (Boland & Alonso, 1982). Attainment of vocational goals by clients and subsequent reduction of dependence on public support programs has always been the primary justification for VR services. Many rehabilitation professionals have resisted inclusion of IL goals out of concern that the vocational emphasis—the basis for the economic argument—would be diluted (Atkins, 1982; Phillips, Fairfax, & Young, 1985; Nosek, 1988). ILCs/ILPs, on the other hand, rely more heavily on a peer approach which includes a strong focus on personal advocacy, and tends to attribute much of the problem as residing in the environment. ILCs/ILPs have not been highly outcome oriented but have focused on providing services which increase an individual's level of independent functioning.

Despite their differences, IL and VR services are not mutually exclusive of one another, either conceptually or in a time continuum. Both are frequently needed by people with disabilities. The literature and the interviews alike affirmed that both IL and VR services are needed to promote opportunities for full independence. Both types of services are supportive of people with disabilities as they go through adjustment periods, enter or reenter the community, and work toward achieving goals (e.g., obtaining an education, getting and keeping a job, establishing and raising a family).

In an ideal world, rehabilitation agencies and ILCs/ILPs would work together to provide a continuum of quality services to consumers. The person might begin services in an ILC/ILP by participating in peer counseling, learning self-advocacy skills, and becoming aware of what services are available in the community. Once the person was functioning more independently, she/he might then enter the VR system to receive some type of job training, necessary adaptive equipment, and/or assistance with job placement. At the same time the person might remain a client of the ILC/ILP to receive ongoing support services.

At the present, however, the situation is far from ideal. Appropriate resources to assist people with disabilities in living independently in their communities are often not available. In most communities, it is necessary for the VR program to assist people with IL needs because there is no ILC/ILP available. At the same time, in many communities, particularly in rural areas, ILCs/ILPs may become heavily involved in provision of VR services because the state rehabilitation agency does not meet the needs of people living in remote areas of the state. However, most ILCs/ ILPs simply do not have adequate funding to provide comprehensive services, including vocational

services, to most people. Under these circumstances, networking and collaboration between rehabilitation agencies and ILCs/ILPs becomes essential from a financial support standpoint.

Because of their primary goal of promoting independence for people with disabilities, ILCs/ILPs are involved in a variety of activities and services which assist the VR program in placing people with disabilities into appropriate jobs. One of these activities is community advocacy which helps create a community environment which allows people with disabilities to participate both socially and vocationally. An accepting environment facilitates the job of the VR counselor. Community advocacy may eliminate physical barriers to community and career involvement. Support services (such as personal assistance and accessible transportation) are more likely to be in place, and community attitudes toward disability are likely to have been altered in a positive way.

ILCs/ILPs are flexible in the manner in which they can respond to the broad range of individual needs whereas rehabilitation agencies and other traditional VR service providers tend to have more narrowly defined missions (Smith & Richards, 1991). In the case of state rehabilitation agencies, as the mission deals specifically with placing the person in the work force, the VR program may easily overlook the day-to-day personal needs that are essential for people to enter and stay in the world of work. Until basic needs such as transportation, personal assistance services, housing, adaptive equipment, and other support services are met, the likelihood of obtaining and maintaining employment is often seriously impaired.

Some ILCs/ILPs that are currently providing VR services appear to be doing so in response to consumer need and demand for vocationally related services. Other centers are providing vocational services as a means of generating operating income, and still others at the request and encouragement of their state rehabilitation agency. Many state rehabilitation agencies are moving toward serving more clients who are severely disabled and are finding that ILCs/ILPs are a viable resource for effectively serving this population.

A basic difference between state rehabilitation agencies and ILCs/ILPs is that ILCs/ILPs by and large do not purchase services for their clients whereas state rehabilitation agencies are primarily purchasers of services. The lack of available funding for ILCs/ILPs to purchase services they are not able to provide "in house" (i.e. purchase of adaptive equipment and housing modifications) severely limits the range and types of services ILCs/ILPs can provide. However, if rehabilitation agencies and ILCs/ILP's develop effective collaborative working relationships, rehabilitation agencies can purchase appropriate services from ILCs/ILPs as well as other needed services from appropriate providers. This benefits both service components. The ILCs/ILPs expand their capabilities through fee-for-service arrangements. The rehabilitation agencies have increased access to community service providers. The ultimate benefit is that the consumer receives appropriate services in a timely manner.

Most ILCs/ILPs do not want to duplicate vocational services which are

available through state rehabilitation agencies. Instead they see their services as complementing those provided by the state rehabilitation agency. Although many state rehabilitation agencies appear to be moving in the direction of providing IL services, they continue to view their primary mission to be addressing the employment needs of people with disabilities. The consensus of the group interviewed for this chapter was that most state rehabilitation agencies' failures, in terms of unsuccessful case closure, could be attributed to the rehabilitation counselor not addressing the IL needs of the person. This problem might be alleviated by a closer working relationship between rehabilitation agencies and ILCs/ILPs.

Questions have been raised by people in the IL field, as well as by rehabilitation professionals, concerning the range and types of vocational services that ILCs/ILPs can and should appropriately provide given the VR resource. Many of the problems which rehabilitation agencies face in providing effective service delivery are related to the bureaucratic structure and associated procedural requirements. Many of the people interviewed could see some degree of danger in ILCs/ILPs increasing bureaucratization and creating the same barriers which state rehabilitation agencies face. Smith & Richards (1991) point out that

> ...many disability-rights advocates, particularly those who have been active for many years and are not directly involved in service delivery, are concerned that independent living centers are beginning to take on the characteristics of traditional social service agencies—agencies with which many persons with disabilities were very discontented at the time that the independent living movement began. (p. 16)

Evidence cited by Smith and Richards (1991) indicating a trend toward more traditional social service delivery approaches by ILCs includes (a) reports of consumers being required to complete intake forms and meet some type of eligibility criteria, (b) centers being less aggressive in community advocacy issues based on a fear of losing funding from businesses or public agencies, (c) centers putting too much emphasis on delivering services (often at the expense of taking on important community issues), and (d) centers relaxing their emphasis on consumer control by taking the easier route of telling consumers what things they should be doing to increase their independence.

Although the trends include both positive and negative elements, it appears that both VR and ILCs/ILPs are moving toward a more coordinated and comprehensive effort to provide more and better services to people with disabilities. If this promising approach is to reach fruition, it is obvious that changes must continue to take place not only with VR services in ILPs/ILCs, but at the legislative and policymaking levels. Adequate funding and resources to insure that needed services are provided will also be prerequisites.

The current challenge (as noted in Chapter 3) is to identify the specific roles that ILR services and ILCs/ILPs can appropriately play in the national rehabilitation system, and to find ways of making them full partners in that system. The results will include increased consumer success in obtaining and (most importantly) maintaining

employment, and in taking control and responsibility for their own lives.

For close linkages and collaboration to be established between VR agencies and ILCs/ILPs, there needs (as noted in Chapters 4 and 5) to be:

1. Clear delineation of appropriate roles and responsibilities for both the VR and IL systems;

2. Assurance that the consumer control of IL services and the professionalism of VR programs will not be compromised by the collaborative relationship;

3. Continuing evidence that the VR system can and will be responsive to the IL consumer and community advocacy functions, and that the ILCs/ILPs can be effective in contributing to vocational outcomes; and

4. An overriding sense of teamwork that joins VR and IL systems as well as other involved delivery systems in working collaboratively to help the consumer achieve his or her cultural and life-style choices.

A review of current practices (Charter 6) has shown that ILCs/ILPs are significantly involved in the provision of employment services, despite many barriers. Even in the face of extremely low levels of funding and an overwhelming array of unmet needs in most communities, the employment needs of people with disabilities are selected by the majority of ILCs/ILPs for service responses. There certainly appears to be much opportunity for different community entities, including ILCs/ILPs, to collaborate in the provision of services which support the achievement of independence on the part of people with disabilities.

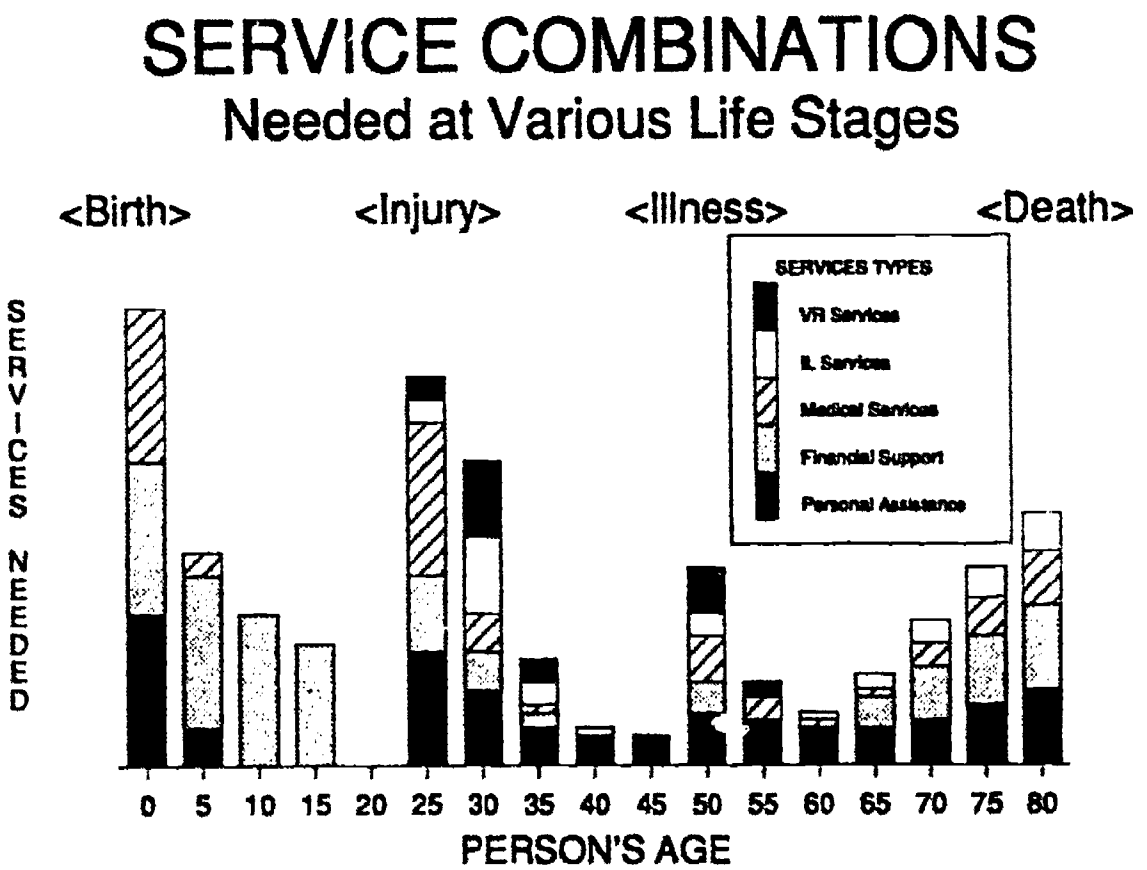
A review of model program confirms that (1) ILCs can be effective providers of VR services, and (2) an effective working relationship between ILCs and state VR agencies can enhance the effectiveness of both organizations in meeting the employment and IL needs of consumers. Employment is an effective means of achieving IL objectives for the consumer. ILCs, because of their flexible, consumer-focused nature, can provide a wide range of effective vocationally oriented services as well as other supportive services to enhance the consumer's ability to function in employment. Both organizations have particular expertise, resources and techniques that, when coordinated with the best interest of the consumer as a focal point, can result in effective vocational programming.

One important point made by several people interviewed was that the IL philosophy encourages a continuum of services from birth, or onset of disability, throughout the life span. VR services, when viewed within the life span of any particular person, is one small part of the adjustment to life/disability. The best hope of achieving a comprehensive service program that meets the full range of service needs of all individuals with disabilities is through effective collaboration between state rehabilitation agencies and IL service providers where service is viewed as occurring throughout the life span.

Bowe (1990) has visually described this view as a graph of services where each different service need is a "blip" on the time continuum. On this graph, traditional VR services would be merely a blip representing time-limited service to assist the person with a disability in achieving a vocational goal. Even the active delivery of IL services to the individual would be limited to specific blips on the graph.

When viewed in the broadest possible terms to include all needed services, the total graph would address needs from birth or the onset of disability to death. The services could include personal assistance, housing, transportation, financial support or assistance, and a wide array of other supportive services, in combinations as needed by the individual. It is possible that, at some points during the continuum, no services would be required. However, the person with the disability would at all times be the controlling factor in determining needed services, and how they would be delivered. (This would, of course, be within the context of age-appropriate capacities for children and youth.) There would also be linkage or "continuity" of services—both among all services needed at any given point, and between services as an individual moved from one developmental stage to the next. This continuum is graphed in a simplified form (see Figure 2).

Figure 2



This chart reflects a lifelong perspective on the service needs of an individual with a disability. As an example, it shows an individual who:

- Was born without a disability and grew through the normal childhood dependencies. By age 20, had no particular service need.
- In midtwenties, acquired a severe disability (such as from a traumatic brain injury or spinal cord injury). Required a combination of services (including IL and VR services)—intensive at the outset. Was treated and rehabilitated over a period of years. By midforties returned to full-time employment, requiring no services other than ongoing personal assistance.
- In early fifties, developed a medical condition which exacerbated the disability and required further treatment. Once more needed a combination of services and was rehabilitated for return to full-time employment, although requiring increased personal assistance and some added support services.
- From midsixties began to experience the gradually increasing need for a combination of services which often accompanies the aging process for an individual with a severe disability.

Note: Although often listed as an IL service, personal assistance is included here in its own right because of its extreme importance and because it is provided through social and medical services systems as well as through IL systems.

Throughout the literature and interviews was a recurrent theme that there is a need for a new paradigm which facilitates a VR and IL partnership to meet the new challenges and opportunities. While any paradigm will require continuing development through interactions among consumers and service providers, the paradigm's general nature is, however, clear. At its best it would focus on the consumer as the driving force for services, and promote partnership among the agencies in responding to that force. It would be characterized by collaboration, integration and networking among the various service delivery systems—all in mutual support of the individual's cultural and life-style choices. All people with disabilities would be able to use this new paradigm, regardless of age or type of disability. And, it would join all participants in expecting and encouraging the maximum level of participation possible by the individual consumer.

IV. IMPLICATIONS

There is little doubt that ILCs/ILPs have a role in assisting consumers to reach vocational goals. However, there is always a cost. If ILCs/ILPs become heavily involved in VR services they run the risk of becoming ineffective in addressing advocacy issues and duplicating an effort specifically delegated to state rehabilitation agencies. Many services currently provided by ILCs/ ILPs, such as socialization skills training, peer counseling, IL skills training, and other services which assist in preparing someone to live independently, unquestionably enhance the vocational potentialof consumers. If a vocational/nonvocational line is to be drawn, where will that line be drawn? There may be a role for ILCs/ILPs in assuming a greater responsibility for influencing rehabilitation agencies and rehabilitation counselors in addressing their clients' needs in a more holistic manner. ILCs/ILPs and state rehabilitation agencies, in concert, can play an important role in educating people with disabilities regarding their rights to specific services, vocational and otherwise. These two entities can also present a unified front in the influence and education of state and federal legislators as well as the general public regarding disability awareness issues.

Clearer conceptualization of the roles of both rehabilitation agencies and ILCs/ILPs would be helpful. Rehabilitation agencies must decide how they will deal with the IL needs of their clients in pursuing vocational goals. They must also determine what the nature of their collaborative relationship with ILCs/ILPs should be in order to best meet the needs of people with disabilities who are served by both service providers.

ILCs/ILPs must also resolve some difficult issues regarding planning their futures and the manners in which they will serve the disability concerns in their communities. ILCs/ILPs are trying to define more precisely the roles they should be playing as service providers, as advocacy organizations, and as community resources for fostering self-reliance (Smith & Richards, 1991).

With the recent passage of the Americans with Disabilities Act (ADA) (PL 101-336), a whole new avenue of access has been opened to people with disabilities. With the potential for increased community access and greater protection of personal rights

comes greater opportunity for people who are severely disabled to enter the world of work and to be fully participating members of their communities. Both rehabilitation agencies and ILCs/ILPs must prepare to work collaboratively toward meeting consumer needs, while assisting with development of regulations, and assure that implementation meets both the letter and spirit of the law.

The field of rehabilitation has made significant progress in the past ten years. More and more, people with severe disabilities are receiving services needed to live and work in their communities. Some people with disabilities receive these services from a state rehabilitation agency, others through an ILC/ILP, and still others through services from both entities. Numerous other service providers are also often involved. Many state rehabilitation agencies are acutely aware of the importance of meeting IL needs as an essential component of their clients' VR plans. Many of these services are being accessed through ILCs/ILPs. At the same time ILCs/ILPs are striving to meet the array of needs presented by consumers, one being the need to achieve financial independence through gainful employment. Both service providers work with consumers in achieving their stated goals. At some conceptual level the goal is often the same for VR and IL services although the techniques, policies, and procedures may differ and may, in some instances, impede their efforts to meet their missions. State rehabilitation agencies view success in terms of the person's ability to attain and maintain employment. ILCs/ILPs more often view success in terms of the person's ability to move toward an optimal level of independence specified by the individual being served. A collaborative effort would increase the probability that every person receiving services would move toward independence in all areas of life.

ILCs/ILPs have been limited in funding and consequently limited in the services they can provide. State rehabilitation agencies, although less limited by funding constraints, are sometimes limited in the services they can provide due to the lack of appropriate providers. Through collaboration, many vocationally-related services could be purchased from ILCs/ILPs, in many cases using Title I dollars, which would provide ILCs/ILPs with broader funding bases and would increase the service provider options available to state rehabilitation agencies.

The experience of both rehabilitation and IL service providers has demonstrated time and again the importance of effective networking, both at the individual level and at the organizational level. In spite of the overwhelming weight of evidence provided by experience, VR and ILCs/ILPs have failed to effectively network in many communities and at the national level. The effectiveness of future service delivery approaches targeted to people with disabilities may well rest with development of a new rehabilitation paradigm. Where DeJong's (1979) earlier analytic paradigm stressed the differences between traditional rehabilitation and the emerging field of IL, the new paradigm must stress the similarities in goals of the two service components in a manner that encourages collaboration, service integration, and networking. Five primary recommendations have been formulated to promote efforts toward development of this paradigm. These recommendations focus on:

- Conferencing between leaders in the fields of IL and VR to define the roles of each service component, to identify areas of service overlap, and to develop effective approaches for dealing with inevitable conflict that result from overlapping responsibilities.

- Examining federal legislation and regulations relating to disability services for the purpose of identifying problems and confusing directives that may contribute to the lack of effective collaboration.

- Reviewing current approaches to consumer involvement in both organizations to determine if more effective collaborative mechanisms that are more engaging and responsive to consumer needs can be developed.

- Examining VR and ILC/ILP relationships to identify factors which have contributed to the establishment of successful relationships and make these findings known in the professional literature.

- Examining unmet consumer needs resulting from lack of available funds and developing strategies to increase funding levels for both Title I and Title VII to more appropriate levels. It should be noted that collaborative efforts between state rehabilitation agencies and consumer-driven organizations such as ILCs/ILPs can be a powerful force in convincing legislators of the need for additional funding resources and/or program initiatives.

These recommendations represent the thinking of leaders in both VR and IL. While the recommendations do not explicate the procedures for achieving the desired goals, with the resources and talents available in both fields, there is no doubt that results can be realized.

Consistent with the recommendations and the general input received, an outline of a disability services paradigm for the nineties is presented. It is offered for discussion purposes, in hopes that it will stimulate needed discussions and interactions which will lead to a better partnership between the VR and IL programs as both attempt to best meet the employment and independence needs of people with disabilities.

A Disability Services Paradigm for the Nineties

Item	*The Suggested Disability Services Paradigm*
Role of the person with a disability	Individual citizen who is seeking services and change in his/her life.
	The driving force for services.
Role of the service provider	Consultant to the individual in own area of experience or expertise.
	Collaborator with consumer and other service providers in developing and carrying out a personalized plan of service.
Definition of problem	Inaccessibility of needed resources or services.
	Absence or incompleteness of needed resources or services.
	Differing, often conflicting, perspectives on the goals and objectives potentially attainable by the individual.
	Differing, often conflicting, perspectives on what is needed to achieve the goals and objectives—including barriers to be overcome and resources or skills to be obtained.
Locus of problem	In the interaction between the individual and family, friends, providers, and community.
	In the interactions (or absence of interaction) among service providers, including both traditional and nontraditional providers.
	In the enforced boundaries and "labeling" of the various professional disciplines, including training, that focuses on different paradigms and does not establish the necessity and methods for collaboration.

Solution to problem	Collaboration of service providers with the individual—including the natural support system, volunteers, and paid/ professional providers—with the forma-tion of shared service goals and objectives in support of the indi-vidual's cultural and life style choices. A personalized plan for needed support services and skills training, with full allowance for individual's life style and cultural choices. Open and reciprocal negotiation of what the individual seeks and what the service providers can offer. Networking as necessary to make available resources and services accessible to the individual. Development of ad hoc coalitions as needed to develop needed resources and services which are not already available. Processes and system linkages for renegotiation of services throughout the individual's lifetime as needed to adapt to changing life stages and needs.
Who controls	In accord with the decisions of the individual, collaborative control that is based on negotiated roles and responsibilities with each participant responsible for own area(s) of activity.
Desired outcomes	Full exercise of citizenship rights. Self-determined cultural and life style. Personal integration and sense of wholeness. Community integration, including social and economic productivity. Life skills and resources (including assistive technology) commensurate with selected cultural and life style.

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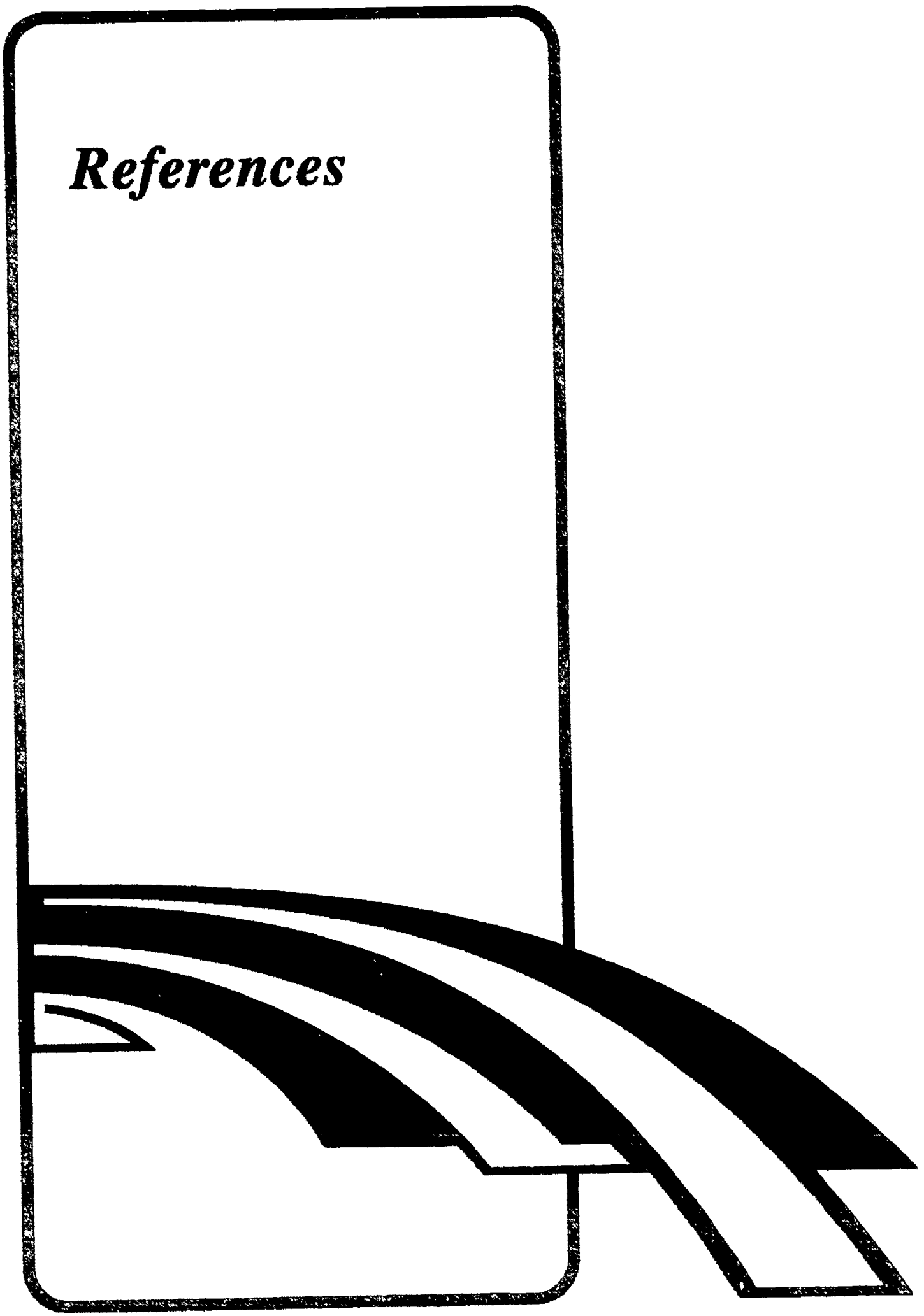

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Appendices

Appendix A

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Appendix C

HIGHLIGHTS
COMPREHENSIVE EVALUATION OF THE TITLE VII, PART B
CENTERS FOR INDEPENDENT LIVING PROGRAM

(A) the numbers and types of individuals with handicaps assisted;

(B) the extent to which individuals with varying handicapping conditions were served;

48,000 persons with disabilities were served during 1984-1985 and 14,000 disabled individuals (family and friends)

75% of consumers responding to the survey were severely disabled (as defined by receipt of SSI, total blindness, or use of attendant care)

24% of those reporting had orthopedic disabilities; 17% were persons who were deaf or hard of hearing; 15% of those reporting were in the other category including stroke, head injuries, diabetes, epilepsy; 12% reporting were persons with visual impairments. Persons with mental disabilities (those labeled mentally retarded and those with psychiatric disabilities) were 8% of the total sample.

(C) the types of services provided;

Centers provided a wide range of IL support services. Almost all responding centers provided the services specified in the evaluation standards, advocacy, independent living skills training, peer counseling, and information and referral. Most centers offered a wide range of other types of assistance to facilitate consumer goal achievement, including services related to housing, attendant/homemaker assistance, transportation, equipment, and social/recreational activities. A majority of the centers also provided other types of nonpeer counseling, and communication assistance such as interpreter and reader services. Finally, over one-third of the centers provided *vocational*, educational, and family support services.

(D) the sources of funding;

The responding centers (121 responded) total annual budgets ranged from $43,000 to $1.3 million, with a median of $240,000 and an average of $323,000, of which the Part B share was about 44%. The second largest source of funds was state moneys, received by 67 (57%) of the centers and comprising approximately 24% of the centers' total program funding. Almost half (58) of the centers received funding from private sources, which comprised about 8% of overall center budgets. Other federal funds and local funds accounted for a very small portion of the centers' budgets (each less than 6%). The longer centers were in operation, the less heavily they tended to rely on Part B funds.

(E) *the percentage of resources commited to each type of service provided;*

Centers devoted an average of one-fourth of their resources to community change and capacity-building activities, with the remaining three-fourths allocated to direct client services. The cost per consumer receiving direct services averaged $435 annually, of which $191 was provided by Part B.

(F) *how services provided contributed to the maintenance of or the increased independence of individuals with handicaps assisted;*

Unlike vocational rehabilitation programs with a focus on employment outcomes, the independent living centers do not have a single goal or measure of success. Rather, they respond to a wide range of particular needs and goals expressed by their consumers, ranging from housing and attendant care to enhanced self-direction and personal growth. Thus, the assessment of program effectiveness must include a wide range of measures.

The 121 responding centers reported that their efforts contributed to raising more than $7.5 million in additional funding for attendant care, adding over 3,000 qualified attendants to local attendant pools, and helping 5,000 individuals secure attendants; making more than 1,800 housing units accessible, and helping 2,250 people improve their housing accessibility; *developing over 1,000 jobs and helping 1,150 individuals secure jobs;* making over 2,300 ramps and curb cuts, and helping 2,000 people move to less restrictive environments. These types of community changes are directly related to disabled individuals achieving equal access to society as well as their ability to either achieve or maintain an independent life-style.

Over three-fourths of the 990 consumers who responded to the evaluation survey reported that they had achieved improvement in a least one life area such as housing, employment, transportation, or education. Almost 90% improvement reported in at least one of the other major life areas. And finally, over half of those responding directly attributed the improvements they had achieved to the help they had received from a center.

(G) *the extent to which individuals with handicaps participate in management and decision making in the center;*

A majority of the 121 responding centers had a disabled director, 55% (66 centers) had Boards with a majority of disabled members, and on average 51% of center staff had disabilities. The community agencies surveyed confirmed that involvement of disabled individuals in center policy direction and management was emphasized by most centers. Thirty-two percent of the consumers surveyed reported some kind of involvement in center operations, including serving on a Board of Directors or an advisory committee, working as paid or volunteer staff, or evaluation services. However, in almost 30% of the 121 responding centers, less than a fifth of the board members had disabilities. Most of these centers operated within an umbrella organization. While disabled

individuals in these centers frequently were involved in staff roles, they were much less likely to be involved in policy direction and management roles.

(H) *the extent of capacity-building activities including collaboration with other agencies and organizations;*

Study findings indicated that the 121 responding centers were involved extensively in capacity-building activities, including collaboration with a wide range of other community and public organizations. A majority of the centers reported that they had provided information to other agencies working with persons with disabilities. Nearly two-thirds of the 100 responding community agencies reported receiving information and technical assistance from centers. One of the community agencies also reported that contact with a center led to an increase in their own efforts to improve community options for persons with disabilities.

(I) *the extent of catalytic activities to promote community awareness, involvement, and assistance;*

Finally, almost three-fourths of the responding community agencies rated the centers as very good or outstanding advocates in their communities. Centers that allocated more resources to community efforts and that involved more consumers in the management and operation of the center were more likely to have greater community impacts.

(J) *the extent of outreach efforts and the impact of such efforts;*

For centers serving rural areas, outreach often involves staff efforts to reach consumers' homes in order to bridge the distances and physical access barriers associated with rural living for people with disabilities. For urban areas, outreach more often refers to publicity efforts and cultivating contacts with private and public community agencies and professionals to ensure their referral of disabled individuals to the center. The results of center outreach efforts were reflected in the consumer survey responses—62% of the 945 consumers responding reported they had learned about the center from other agencies, 15% had heard of the center directly from center staff and publicity, and 23% learned by word of mouth from other consumers. While the impact of outreach is difficult to assess, the disability distribution of consumers served by centers is similar to that of the nation as a whole.

Conclusions

The Title VII Part B Centers for Independent Living Program is successfully helping large numbers of disabled citizens maintain or improve their ability to live independently in their communities. They accomplish this through individual and direct services, referral to others resources, and activities targeted towards community change. There remains much diversity among centers in targeted client populations, services offered, management practices and systems in place, and involvement of

individuals with disabilities in center planning and management. Some of this diversity is an appropriate response to variation in local needs. However, it also appears that many centers would benefit from increased guidance and technical assistance, greater information exchange with other centers, and increased levels or stability of funding. Also, the centers collect a wealth of information about their services and the consumers they serve that could be more valuable to program planners and policymakers if definitions and measures were uniform across centers.

Berkeley Planning Associates. (1986). Comprehensive evaluation of the Title VII, Part B of the Rehabilitation Act of 1973, as amended, centers for independent living program. Final Report. (Contract #300-84-0209.) Washington, DC: U.S. Department of Education.

Appendix D

DISABLED PEOPLE'S BILL OF RIGHTS AND DECLARATION OF INDEPENDENCE

Preamble:

We believe that all people should enjoy certain rights. Because people with disabilities have consistently been denied the right to fully participate in society as free and equal members, it is important to state and affirm these rights, regardless of race, creed, color, sex, religion, or disability.

1. The right to live independent, active and full lives.
2. The right to equipment, assistance and support services necessary for productivity, provided in a way that promotes dignity and independence.
3. The right to an adequate income or wage, substantial enough to provide food, clothing, shelter and other necessities of life.
4. The right to accessible, integrated, convenient and affordable housing.
5. The right to quality physical and mental health care.
6. The right to accessible transportation and freedom of movement.
7. The right to training and employment without prejudice or stereotype.
8. The right to bear or adopt children and raise children and have a family.
9. The right to free and appropriate public education.
10. The right to participate in and benefit from entertainment and recreation.
11. The right of equal access to, and full use of all businesses, facilities and activities in the community.
12. The right to communicate freely with all fellow citizens and those who provide services.
13. The right to a barrier free environment.
14. The right to legal representation and full protection of all legal rights.
15. The right to determine one's own future and make one's own life choices.
16. The right of full access to all voting processes.

Adapted from CIL at Berkeley, CA

Appendix E

Interview Participants

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Michael Winter, Executive Director, Center for Independent Livirg, Berkeley, California.

Bobby Simpson, Director, Arkansas Division of Rehabilitation Services, Little Rock, Arkansas.

Appendix F

Arkansas Research and Training Center in Vocational Rehabilitation's National Survey of Independent Living Centers' Employment Services and Related Activities

Instructions: Please answer all questions as accurately and completely as possible. Your individual Center input will be held in confidence; only group results will be reported.

Center Name: _____

Your Name: _____

Title: _____

Address: _____

_____

Telephone: _____ TDD _____

1. What is your full-time equivalent personnel in the following categories:

Direct Service Deliverers	Administrative Staff
A. _____Professional (degree and certification)	C. _____Professional
B. _____Paraprofessional (nondegree or peer)	D. _____Paraprofessional or Support

2. Of your total Center staff, what is the full-time equivalent personnel with disabilities?

_____

3. What percentage of your ILC board are persons with disabilities?

_____

4. How many years has your program been operating?

_____

5. What is the approximate total population of the area served by your Center?

_____

6. How many miles from the Center to the farthest point in the services area?

_____

7. List estimated population percentages of your service area.

_____Urban/Inner City
_____Rural
_____Suburban

8. Approximately how many different consumers will you serve this year?

_____

9. Do you serve a cross-disability population? Yes___ No___

10. If you target one or more specific disability groups, please list:

_____

_____

Please indicate the types of services directly provided by your Center by checking the codes explained in these guidelines.

MA Major Service:	A substantial amount of the Center resources are invested.
MI Minor Service:	Service is provided but it is considered a secondary or as time and resources permits service.
IN Insignificant Service:	Not provided at all or only rarely.

MA	MI	IN		
____	____	____	11.	Academic Educational Services
____	____	____	12.	Adaptive Equipment Services (includes van repair)
____	____	____	13.	Advocacy (individual, community and/or political)
____	____	____	14.	Case Management Services
____	____	____	15.	Community Support to Accommodate Persons with Disabilities (consultation on barrier removal, accommodations)
____	____	____	16.	Employment/Vocational Services
____	____	____	17.	Personal Life Support Services (meals, housekeeping, emergency)
____	____	____	18.	Mobility Training
____	____	____	19.	Independent Living Skills Training (exclude mobility training)
____	____	____	20.	Financial Services (counseling, financial support)
____	____	____	21.	Housing Services/Assistances (excluding long-term residence)
____	____	____	22.	Long-term Residential Services
____	____	____	23.	Information and Referral
____	____	____	24.	Medical Services (including PT & OT services)
____	____	____	25.	Legal Services
____	____	____	26.	Personal Attendant Services
____	____	____	27.	Peer Counseling/Consultation
____	____	____	28.	Professional Adjustment Counseling (psychiatric, psychological, family, etc.)
____	____	____	29.	Reader Services

____	____	____	30.	Transportation Services
____	____	____	31.	Sheltered Workshop
____	____	____	32.	Recreational/Social Programs
____	____	____	33.	Supported Work Programs
____	____	____	34.	Transitional Employment Services
____	____	____	35.	Placement Services
____	____	____	36.	Vocational Counseling/Guidance
____	____	____	37.	On-the-Job Training
____	____	____	38.	Homebound or Home-based Employment Services
____	____	____	39.	Work/Labor Groups
____	____	____	40.	Other:
____	____	____	41.	Other:
____	____	____	42.	Other:

43. Do you provide any type of career/vocational assessment services? Yes ___ No __

Please check the types of assessment services provided by your Center:

____Aptitude or ability testing
____Work tolerance
____Assessment as a part of work activity
____Interest testing
____Informal assessment only
Other, please list: _____
_____
_____

Rate these services in terms of the explanation provided earlier.

____Major
____Minor
____Insignificant

Explanation of assessment services, if needed:

44. Do you provide any type of occupational skills training? (Examples: computer, secretarial, etc.) Yes ___ No __

Rate these services in terms of the explanation provided earlier.

____Major
____Minor
____Insignificant

Explanation of occupational skills training, if needed.

45. Do you provide any type of formal employability or general career development skills classes or services to increase client's abilities (i.e., personal skills) to participate in the work force? Yes ___ No __

Please check the types of classes provided by your Center:

____Career Planning
____Lifecareer Coping (e.g., stress management, interpersonal skills, etc.)
____Job Seeking Skills
____Work Hardening
____Basic Work Skills (e.g., punctuality, responding to supervision)
Other, please list: _____
_____
_____

Rate these services in terms of the explanation provided earlier.

____Major
____Minor
____Insignificant

Explanation of services, if needed:

46. Are you involved in types of activities that are designed to increase the job opportunities in the community for persons with disabilities? Yes ___ No __

Please check the types of services provided:

____Political initiatives to create job opportunities
____Public media messages targeting employment
____Consultation with business or industry specifically to modify work settings
____General/educational contact with business or industry to increase job opportunities
Other, please list: _____
_____
_____

Rate these services in terms of the explanation provided earlier.

____Major
____Minor
____Insignificant

Explanation of services, if needed:

47. Do you receive any special or nonbase grant funding to provide employment or vocational services? Yes ___ No __

Please check or list the sources of this funding.

____State DVR
____Private Business or Industry
____Foundation
____Federal Government Grant
____State Government Grant (Other than DVR)
____Job Training Partnership Act
Other, please list: _____
_____
_____

Please return this form to the address below in the enclosed stamped envelope within two weeks. Again, if you have any questions, feel free to call.

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